



UNIVERSITY OF CANTERBURY  
TE WHARE WĀNANGA O WAITAHA

# Beyond 'Breaking Bad News'

*Clinicians' experiences of disclosing a life-limiting illness to  
their patients*

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## Abstract

The preference for open disclosure of a terminal diagnosis has become widespread in western societies. Disclosure practices are influenced and shaped by medical culture, the organisation of medicine and cultural and social expectations of the medical management of dying. In the literature clinician's performance of telling bad news to patients and their families is positioned within an array of expectations and critique. Within this are theories and commentaries on the motivations of physicians and the degree to which they still determine when and how much information on a terminal diagnosis is communicated. Yet little is known of the clinicians experience presenting a life threatening diagnosis to their patient. This research looks beyond the mechanisms of communicating bad news to examine how clinicians manage, cope and sustain their emotions over cumulative experiences of telling bad news to patients.

**Method:** A qualitative study drawing on symbolic interactionist framework the research explores clinicians' experiences of disclosing a terminal diagnosis or prognosis to their patients and families. Semi-structured interviews were conducted with five clinicians from a range of medical specialities in New Zealand. Narrative analysis of the data revealed the practice and processes of disclosing a terminal diagnosis to a patient are more nuanced and less distinct from an absolute of truth-telling or not. Balancing hope and honesty, clinicians communicate bad news to patients generally over a long period of testing, diagnosis, treatment and retesting. Consequently the experience for the clinician is mediated and managed through this trajectory of care. Positioned to negotiate an orderly and medically managed dying process with their patients, there is a risk clinicians can be demoralised when disruptions to the expected response to care occurs. Recognising broader societal responsibilities to consider the position of clinicians who act on our behalf and reflect on the generosity beyond the care required is called for.



# Chapter 1

## Preface

In February 2013, my father received test results that indicated a possible change in the status of the prostate cancer he had been diagnosed with, and treated for, over the previous seven years. He was angry because despite his requests, regular tests had not been considered necessary by his GP. The change in diagnosis, from an illness he was told would be unlikely to end his life before the natural course of old age, to the likelihood of dying within a few years, was confirmed during an appointment with an oncologist.

In the process of this being disclosed to my parents something happened. Two people in their early eighties, who felt let down by their GP, were in the difficult retelling of this diagnosis to family over the coming days, able to articulate a high level of trust and a certain intimacy befitting a long term relationship with the oncologist. Initially, I was focused only on the prognosis and what the journey ahead would mean for us. Then as I spent time with my parents and witnessed their re-telling of this story to close friends, I noticed how often the experience of the disclosure with the oncologist was mentioned. Their experience was critical to their re-ordering of the future.

I became intrigued with how such devastating news had been communicated to two people who clearly had expectations of a lot more living to do. Disclosing the diagnosis had not thwarted their sense of a future. Rather it had been re-adjusted, so hope for more living and a carefully managed end was facilitated by the plan of action confidently offered by the oncologist. Their deep sense of trust that his care was authentic ran counter to my expectations of how they, as aged people in a busy oncology department, would be treated. Assured of the care and the plan ahead, we were all able to salvage and re-order our hopes for more time with minimal suffering.

Over the course of my father's illnesses the relationship with his oncologist was challenged as his trust in the care pathway offered was constantly renegotiated, most critically when treatments failed. Exacerbated by the disruption of lumpy and insensitive transitions to and from palliative care, his GP and oncology registrars, my father's trust in a medically determined future

waned. Finally, in the unexpectedly abrupt and difficult dying phase when his illness veered off course, the trust was lost. Two weeks before his death he mustered the strength to accept further radiation treatment suggested by his oncologist. When he arrived he discovered his oncologist was scheduled to attend another clinic. I watched my father physically diminish from what my parents described as ‘blow’.

I knew then he didn’t come for the treatment. It was something else. Perhaps he was seeking reassurance or an understanding he could trust this man to provide? Maybe there was more; perhaps he had something to ask or say? Characteristically though, I do know my father would have wanted to shake his hand, look him in the eye and say thank you and goodbye for the last time. That was his gift. Maybe that was all he wanted to do.

I wondered what it was like for his oncologist to be in this relationship repeatedly with the countless patients in his waiting room who all bore startlingly similar characteristics. I wondered if, or how he would know my father had died. What would it mean for him when in many respects biomedicine had failed to deliver on the plan? I recalled the exultation experienced when initial treatments were deemed successful and I questioned if endings were avoided because the confrontation with death when there was nothing more that could be offered might be awkward or even unbearably difficult. I began to consider how clinicians navigate, negotiate and cope with this most critical process, that situates them so intimately with another person’s reconciliation with death.

My experiences with my father ran parallel to, and directly influenced, the development of the research project for this thesis. Originally expecting an extended ‘terminal’ future, I had anticipated completion of this research long before his death. On reflection, had that occurred, I may have missed the gift he gave *me* in dying as he did. Throughout this research process I have thought about his journey, contemplating what happened, in between the beginning and end, and what could be different.



## Chapter 2

# Introduction

Disclosing a terminal diagnosis or prognosis to their patients, clinicians have been described as intermediaries or “master of ceremonies” to the transition from health to life-threatening illness and for some, death (Boland 2013, p. 230). Clinicians must bear the burden of witnessing the suffering of others on a daily basis, in a culture where emotional stoicism is expected and little support is available to discuss feelings such as loss and grief. It is easy to forget, in the blame and critique of their performances disclosing a life-threatening diagnosis or prognosis, clinicians also suffer:

*“Through their willingness to be present to us in our most vulnerable moments they are forever scarred with our pain—a pain that we the healthy want to deny or at least keep at arm’s length (Hauerwas in Chapple, 2010, p. 226).”*

The expectation of medical professionals to distance us from death, through cure or producing pain-free, peaceful death could be considered a way of coping with the more recent preference for open-awareness of death and dying. We may want to know if we have a life-threatening diagnosis but we also want to believe in the possibility of the ideal good death promulgated in hospice discourses.

As such, the disclosure of a life-limiting illness situated within this cultural and social landscape of paradoxical expectations, is a sociological event. At the threshold of the illness trajectory for dying patients, it is interesting that clinicians’ experiences of disclosure, specifically in New Zealand, have been largely under-researched.

The purpose of this thesis is to locate experiences of five New Zealand clinicians from different medical specialties in the cultural and social context of the medical management of death and dying by drawing on data gathered through semi-structured interviews. In light of ongoing criticism in much of the patient literature, I am interested in how clinicians orient themselves to the disclosure experience and cope with their role of telling bad news.

When I asked how clinicians experienced disclosing a life-limiting illness to a patient their first response was to talk of when they would or would not be doing this, and then who would be, and why. When I asked clinicians what it was like to tell someone there was nothing more that could be done for them, invariably I heard a resolute denial: “I don’t.” Why? Because drawing on their medical construct there was always something more that could be done for the patient. Working from this angle responses to my questions led to stories of diagnosis that dominated the disclosure experiences over the trajectory of care for patients.

I argue that disclosure of life-threatening illness or prognosis is more than telling a patient the results of a diagnosis. The focus of disclosure invariably turns to what next? Clinicians are tasked with “brokering” the patients’ engagement in the medical management of their illness which follows (Timmermans 2005, p. 993). Scripts informed by professional and social expectations determine what is able to be brokered by the clinician. Professionally clinicians’ belief in the orthodox medicine they can offer and expectations of patients to accept treatment and care within this paradigm informs how disclosure processes are managed. Always having something more to offer their patient and anticipating patients will *always* accept these offerings also establishes expectations more broadly in society. Clinicians are positioned to stave off death, or deliver a peaceful, pain free death though this is largely dependent on the patient adopting the role of the valiant warrior, fighting to the end against death. Patients who consider alternative approaches to dying disrupt these social scripts, threatening the orderly and managed approach to life-threatening disease.

When negotiations fail and the patient rejects their care, or their bodies are unable to be managed, clinicians do report experiencing a sense of failure. How clinicians are positioned to manage the disclosure of a life threatening diagnosis or prognosis to their patients and the negotiation of care to follow is the focus of this research.

## Road Map to Thesis

Consequently a series of questions emerge: what influence does medical culture have on the clinicians’ experiences and what is their awareness of these influences in the context of the disclosure process? How do clinicians manage the presentation of a life threatening diagnosis or prognosis to their dying patients? What emotions do they experience and how do they deal with the feelings that emerge from this situation? How much of their experiences are influenced and shaped by social and cultural expectations of the medical management of death and dying? How much do these expectations constrain and enable clinicians in how they can care for their patients?

The rationale and methods used to investigate the clinicians’ experiences of disclosure is outlined in the methodology chapter which follows, along with

a discussion on the challenges and limitations of these research processes. The methodology chapter is followed with a review of the relevant literature, organised to represent thematically relevant debates and dichotomies of disclosure I draw on in the analysis. To augment this context I continue with biographies of each clinician who generously contributed to this research. These biographies act as a backdrop as the reader and transition into the fourth chapter, which offers an analysis of three clinicians' experiences of diagnosis and disclosure. Understanding clinicians' experiences from their respective position along the trajectory of medical care informs their responses to the experience. Frequent exposure and expectations of good survival outcomes, mediates the clinicians experiences and often turns the patient's focus from the risk of dying toward the fight for survival.

Diagnosis is the starting point for clinicians to establish their orientation to disclosure. Diagnosis also illustrates the temporal ordering of disclosure toward a trajectory of care where the clinician always has 'something more they can do'. At times offering a certain predictable order to the disclosure experience, the findings suggest regularity and routine facilitate the clinicians' presentation of their professional identities to patients in the clinical encounter.

In Chapter 5 I explore the influence of medical culture on the clinicians' experiences of disclosure through the analysis of another three of the clinicians' narratives. These narratives bring to the fore powerful discourses of clinicians' responsibility to do no harm to their patient. Adhering to this ethos extends to managing their own emotional responses to patients lest they upset or surprise them with their own feelings of loss or sadness. Clinicians are also taught to control their emotional responses lest this interferes with their clinical judgement.

However the uncertainty of how patients will respond emotionally, physically and intellectually emerges when clinicians talk about more challenging experiences in Chapter 6. I explore how in these situations, when the clinicians' actions are halted or fail to achieve the expected outcome, their performance is disrupted and narratives of failure emerge. This raises questions of how clinicians can be supported to care for their patients and be permitted to respond with other scripts.

In the concluding chapter I bring together the pieces of stories interspersed in the clinicians' narratives as exemplars of Frank's (2004) concept of medical generosity. From these narratives I came to see that the responsibility to give permission for them to fail, to speak from other scripts, to grieve, and to socialise newly trained doctors to a "remoralized" ethic of care lies with us all (Frank 2004, p. 25). In this way we can all forgive ourselves when we "cannot achieve some preconceived image of dying right" (Nuland 1994, p. 262).



## Chapter 3

# Methodology

### Introduction

The decisions that shaped how this research project was identified, designed and executed had their genesis in the personal experiences of witnessing my father's relationship with his oncologist. There was a personal motivation driving my interest. The choice to pursue research that sought to explore how consultants involved in end-of-life care in New Zealand experience disclosing a terminal diagnosis, reflects my belief that knowledge is not objective but rather constructed, shaped and informed from the experiences of both the research participant(s) and the researcher.

Visits to the oncologist with my parents allowed me an insight into a process of end-of-life care that I had not known and which ran counter to my pre-formed expectations of the patient-doctor relationship. In my own sense-making of these experiences I sought understanding and context from the research literature of how doctors experience what was for my family, a significant relationship into the unknown; the trajectory of a terminal illness. Reviewing the literature initially generated a wealth of material on the patient's experience of receiving a terminal diagnosis, or what is frequently referred to as 'bad news', however, there was little reference to the doctor's experience of giving the news. Although it appeared little was known about the physicians' experiences in the literature, much had been discussed in relation to their communication style and most of this negatively.

I was seeking an understanding of what it was like for them to tell another person their life may end sooner than they had expected. I sought to understand how they experienced this and why. This led to the physicians' meaning-making of the experience of disclosing a terminal diagnosis within this shifting social context becoming the focus of my research.

Developing an understanding of what it might mean to be a doctor experiencing the processes of disclosure did not assume there was a hypothesis to be tested, or that a body of knowledge about their experience existed that could

be tested with the New Zealand doctors I recruited to the research. Rather, the research was approached from the position that this knowledge would be constructed from the lived experiences of the doctors and co-constructed from my actions and reflexivity as the researcher interpreting and analysing these accounts.

What I learned was the inherent limitations of seeking to uncover and reveal the personal experiences of research participants as an outsider to the medical profession within the constraints of a small research project. I also learned the value methodological challenges offer to furthering my understanding of what it means to do social research.

This chapter outlines the research design used to guide the sociological exploration of how doctors in New Zealand experience the process of disclosing a terminal diagnosis to their patients. Elements of the research design are presented beginning with the approach to the research that led to the selection of the methodology underpinning how the research was conducted. It follows with discussion of collecting and analysing the data and concludes with a section on the methodological considerations, including limitations of the research project. Interwoven in the presentation of the mechanics of the research process are examples from my journal of the reflexive experience of ‘doing’ social research that generated personal and pragmatic dilemmas.

## Approach

Given the nature of the research question and the scarcity of literature from the experience of New Zealand consultants, it made sense to use a qualitative, rather than a quantitative or mixed-method approach, to develop a rich account of their experiences and from this identify themes of how meaning gets made in the New Zealand context.

Applying an interpretative-constructivist approach to this issue was appropriate as little exploratory research had been done that considered the consultants’ experiences. In this way, I used an inductive reasoning approach to the research design and sought to develop an understanding of these experiences from what the research participants shared.

This approach premises the relationship of the researcher and the research participants as actively constructing shared understandings. Acknowledging the researcher’s role in these co-constructions I learned how significant my own subjectivity was on the research process. I formulated a research question to understand an experience in my own life, and using Interpretative Phenomenological Analysis (IPA) as the research methodology thought I could probe deeply into the experiences of the research participants.

What emerged from the data I collected was not the deeply personal material I had expected. After months analysing the data trying to locate the insider’s perspective of the consultants’ experiences of disclosure, I became

lost. With the department's support I was offered a change in supervision and with that, an understanding of the methodological issues inherent in how I had approached the research question. A shift in perspective allowed me to work with the data I had in front of me. With consideration and understanding of the methodological limitations of IPA for this research project I drew on symbolic interactionism to align the analysis more closely to the data. I was able to retain the focus on the experience of a phenomenon and the meanings ascribed to the experience but with less grand claims to understanding what it is like to live in the consultants' worlds.

I realised I could not access the consultants' inner worlds. My analysis could only be based on what consultants said to me about their experiences and the constructions or interpretations as social, rather than psychological entities, we both made of the phenomenon of disclosing a life-limiting diagnosis and prognosis to a patient. This change of approach and the implications for the research are discussed more fully in the section on methodological considerations.

## Methodology

### Grounded Theory

Initially, when I began to consider the research project, I was attracted to grounded theory as it aligned to my approach that knowledge is constructed, allows for inductive enquiry, and gives voice to the participants being researched. Within the multiple perspectives of grounded theory I orientated to the constructivist position primarily because this approach provides a departure from the direction of the classical interpretation of the methodology that seeks to identify and explain patterns of behaviour abstracted from the research data (Charmaz 2006). The focus of this research was to explore experiences and interpret the meaning-making of those experiences so if there was no discernible 'pattern of behaviour' emerging that did not mean that the research findings were less valid.

The more constructionist approach to grounded theory is concerned that seeking to identify and conceptualise behaviour patterns from the data analysis risks losing the voice of the research participants (Charmaz 2006). Researching experiences from an interpretative-constructivist position steered me away from abstracting behaviour patterns, causality and I thought, seeking to discover truth(s).

However, this did not mean I wanted to simply engage in a descriptive story-telling of the experiences of the clinicians. Rather I wanted to develop an interpretative account of what it is to be having these experiences and how this contributed to a sociological understanding of the phenomenon.

To develop a rich, detailed, qualitative account of how clinicians experience disclosing a life-limiting illness to their patients I wanted to understand how

they felt about the phenomena and then situate their accounts in the social and political shifts influencing ‘truth-telling’ in the broader realm of medicine. It was also likely that consultant specialists and mid-career clinicians would not only have had more opportunity to experience these disclosures but may also be experiencing this within a wider range of medical specialties given the increasing rates of co-morbidities associated with longer life-spans.

At the time, the question and challenge was how I would recruit the requisite number of consultants to meet the expectations of data saturation using grounded theory in the timeframe available to complete a Master’s thesis. Conservative estimates for data saturation were a minimum of fifteen to twenty participants with the potential for more if new data was still adding insights to the investigation. Because of the nature of the research focus, it was anticipated that it may be difficult to recruit large numbers of consultants in New Zealand willing to participate in multiple rounds of data collection given constraints on time.

Facing the likelihood of only being able to recruit a small sample of clinicians brought to the fore some of my underlying assumptions about the validity of the research. I reconciled that generalisability was not an aim. Instead the aim was to develop a detailed analysis of experiences and how these may have changed over the consultants’ medical careers.

### **Interpretative Phenomenological Analysis**

In discussions with my supervisors, they suggested Interpretative Phenomenological Analysis (IPA) as a more suitable methodology. Although IPA originates from health psychology and is focused on individual experience, rather than social context, there was confidence it was possible to adapt this approach toward a sociological analysis (Smith 2011).

With its roots in symbolic interactionism and phenomenology, IPA allows for meaning to be explored from an interpretative-constructivist paradigm (Smith 1996). Understanding people’s lived experience and the individual meaning they attach to their experience is the central focus of IPA. Like phenomenology, IPA is concerned with an individual’s perception and also recognises the importance of the interaction of the researcher and the research participant from which meaning occurs (McPherson, Wilson, and Murray 2007; Smith, Larkin, and Flowers 2009). From a symbolic interactionist perspective, those meanings are only “obtained from a process of interpretation” (Smith 1996, p. 263).

Data collection methods are selected to support this approach (Starks and Trinidad 2007; Smith, Larkin, and Flowers 2009). Smith et al. (2009) also suggest that an ideal sample size for a small research project such as a masters’ thesis, is no more than three to allow for a thorough analysis of each interview transcript and “say something in detail about the perceptions and



understandings of this particular group” (Smith, Larkin, and Flowers 2009, p. 55).

Importantly, I was attracted to IPA because it sought to get an “insider perspective” on an individual’s experiences by generating rich, in-depth descriptions for analysis (Smith, Larkin, and Flowers 2009, p. 150). I anticipated using an IPA approach would enable me to uncover and reveal the nuances and complexities of the clinicians’ experiences of telling patients they had a life-limiting diagnosis or prognosis from the interviews I conducted and the analysis that followed (Smith, Larkin, and Flowers 2009).

Finally, IPA offered a sense-making of its own through the ongoing process of self-reflexivity using techniques such as journaling and bracketing to capture my presuppositions (Smith, Larkin, and Flowers 2009). These practices helped me to reconcile my doubts about the overt influence I may have on the research when I was so close to the issues and are discussed in the section on reflexive practices.

## Methods

### Sample

In using IPA I was seeking an understanding of the clinicians’ experiences to analyse how they make meaning of disclosure situations. Data collection methods called for a particularly small sample size to produce a “sufficiently penetrating analysis” (Smith, Larkin, and Flowers 2009, p. 57). IPA tends toward sampling a more homogeneous group through purposive sampling (Smith, Larkin, and Flowers 2009). The group targeted for recruitment in this research was medical consultants that have had or are currently involved in, aspects of end-of-life care. This was to provide some homogeneity in terms of experiences in their career as medical students and as mid-career consultants.

It was agreed I would try to recruit four to six participants from a range of medical specialties to explore the issues for consultants who may be engaged at different stages and times in the process of disclosing a terminal diagnosis to their patients. This included consultants within academia and medical institutions.

The sample was not specifically orientated to achieving a gender, age or ethnic balance, as statistically overall in New Zealand medical specialties are largely comprised of European males aged between 50 and 54 years, with the exception of general practice where women are more evenly represented at 45% in this speciality (Medical Council of New Zealand 2012). Largely these statistics were reflected in the sample for this research. Five participants, one woman and four men from specialties in palliative care, oncology, surgery and general practice were interviewed. Although information on age was not solicited, each participant offered an indication of their age in the context of

discussing experiences over the life of their careers. Based on this information the range of ages was approximated at between fifty and sixty-five years. Homogeneity in ages was anticipated because the research targeted consultants who were likely to have well-established careers with considerable experience of end-of-life care and also aligns to the statistical profile of specialists in New Zealand (Medical Council of New Zealand 2012).

### **Recruitment Process**

Recruiting research participants commenced by making contact with people I knew personally who were medical professionals and inviting them to participate in the research. Unsure of their response because of the research focus it was deeply encouraging to receive an immediate and positive response to the invitations. The first interview was quickly confirmed and then a meeting with the second recruit to reconnect and discuss the research prior to scheduling an interview was organised. At that meeting the recruitment effort was bolstered by an unsolicited offer of assistance to provide introductions to colleagues that would likely agree to participate in an interview. This version of ‘snowballing’ where parties are invited to pass on information about the research to potential participants of their acquaintance was identified as part of the recruitment strategy early on. However, I had not anticipated offers of support immediately (Atkinson and Flint 2003). Buoyed by this response I held back from implementing the cold-calling technique of approaching consultants I didn’t know via email or phone to introduce myself and the research project.

The early and unanticipated momentum of recruitment informed my expectation that further participants would be confirmed in a similar time frame. However, this was an expectation that proved to be unrealistic and challenging throughout the recruitment process. Understandably consultants are dealing with competing priorities and communications were frequently delayed. At the same time as I was recruiting participants my father’s illness progressed unexpectedly such that maintaining recruitment activities became onerous. Consequently the momentum of the recruitment was disrupted as study was suspended. After a break of four months, I reengaged with the recruitment. This time the pressure on the snowballing technique intensified after several attempts at cold-calling failed to generate any responses. I went back to the first two participants for assistance and again was provided with support and introductions. One of these resulted in the confirmation of another interview in four weeks and the other a phone call agreeing to an interview with the time to be agreed via email.

In the interim the second interview was held which along with the first interview, referenced the role of General Practitioners (GPs) in the diagnosis process with patients. In selecting the sample group, GPs had been considered less integral to the disclosure process with an assumption that medical spe-

cialists would most likely determine and communicate diagnosis directly with patients. This was an assumption that was challenged by the data from the first two interviews and as such, warranted the inclusion of GP's experiences in the research data. Delays in recruiting participants proved advantageous in this instance because it provided time and flexibility to reconsider the sample criteria against this new information and make the decision to include GPs. Again, I relied on personal networks to assist with successfully recruiting a GP to participate in the research.

Following the completion of four interviews I became concerned that the fifth interview may not proceed as I had not succeeded in confirming an appointment for the interview. Although the target number of participants of between four and six meant it was acceptable to complete the fieldwork with four interviews, the inclusion of another consultant's experience from a different medical speciality temporarily allayed an underlying concern about the data I was collecting for the interrogative analysis that lay ahead. Unable to draw a line under the recruitment phase proved distracting and disconcerting while shifting to the next stages of analysis. Hence it was a moment of relief when the fifth interview was finally scheduled providing closure on the recruitment phase and perspective on the need to be patient, resilient and tenacious as a social science researcher.

## Data Collection

Smith, Larkin, and Flowers (2009) suggest that to develop a detailed examination of how people understand and make sense of things requires flexibility with the data collection methods and as such, suggests the use of semi-structured interviews. Given the type of information sought from the interviews was a narrative description by consultants of how they experience and make sense of disclosing a terminal diagnosis to their patients, this method was used to generate much of the data. Semi-structured interviews also align to the constructivist approach as there is the opportunity for reciprocity to develop with the researcher and participant and to acknowledge the co-construction of data and meaning-making (Creswell 2009).

## Research Questions

A schema of research questions was developed in preparation for the interviews. I found this process difficult as every draft I produced had traces of my presuppositions with questions that assumed the process of disclosure was difficult or problematic, leading to anguished meaning-making for the consultants. I sought assistance from my supervisors and trialled the questions with a friend but throughout my journal entries the research questions remained an unresolved issue. Should I be consistent and ask the same questions? How much did this approach risk guiding the interview away from the elusive reve-

lations I thought I should be uncovering? This is evidenced in a journal entry following the third interview I wrote:

In the interview I was conscious of questions I had asked in the other two interviews and thinking I should follow a consistent format but it didn't flow that way. Each interview has been so different from each other and my expectations that I am still left feeling like I'm not doing it right and anxious that I may have missed opportunities to get to the 'good stuff' (Journal entry, 9 May, 2015).

In the end I used the schema mostly as a framework for each interview though many times the interview veered off in other directions. Prior to each interview, I reviewed the questions against the material I had, to identify possible gaps that could be included in subsequent interviews. Each interview was different and unique. Some shared a rhythm that intensified as the conversation moved toward the personal, while one was determinedly impersonal as my journal entries reflect:

Kept feeling like I was being prevented from asking more than the superficial - answers were repetitive and stayed within a small radius of work. Am I asking the right questions? (Journal entry, 5 March, 2015).

This interview we got into the experiences pretty quickly which gave it a different momentum. It seemed more intense and personal (Journal entry, 8 April, 2015).

Interviews varied in length, averaging 90 minutes with the exception of the first interview which was over two hours. All of the interviews took place in workplaces scheduled in between and after, the intensity of clinics, appointments, meetings and emergencies. I was acutely aware that my presence represented a significant disruption to an already overfull day and wanted to ensure I minimised the toll this took on the participant. I always arrived punctually, got better at time-keeping and monitoring for shifts in the dynamic that indicated I may be labouring an issue. I found at the conclusion of each interview there was a process of re-orientating again to the role of researcher and making sense of being an outsider to the participant's world.

Following each interview, I transcribed the audio-recordings and individual transcriptions were made available to each research participant to confirm accuracy and provide an opportunity to make modifications if they wished to do so. Pseudonyms were used to protect the identities of all research participants and all other identifiers were protected, including location. Any identifying information captured in the audio-recordings and transcription was excluded. Returning the transcripts to each participant facilitated a further opportunity

to thank participants for their time and support of the research following the interview, affecting in part a closure to the fieldwork. Only one participant returned their transcript which had extensive track changes to both clarify the meaning of what they had said and how it was said, editing out many instances of repeated words and turns of phrase.

### Reflexive Practice

The complex and nuanced relationship as researcher to the participant making sense of their meaning-making proved demanding and engaging throughout each stage of the research process. Drawing on the Heideggerian phenomenological approach, Larkin, Watts, and Clifton (2006, p. 108) suggest that attempts to show the research participant “on its own terms” divorced from any preconceptions, assumptions or expectations will fail. This is because the researcher, like the participant, as “a ‘person-in-context’ (and hence an observer, indelibly situated within the meaningful world that we observe) we can never fully escape the ‘preconceptions’ that our world brings with it” (Larkin, Watts, and Clifton 2006, p. 108).

Throughout the research process I kept a research journal. As much as possible, I wrote freely about my experiences, fears, questions and understandings. For example, very early into the research process I was questioning the methodological approach:

I’m reading Smith et al., (2009) to understand more of IPA. I am supposed to be looking at the everyday, phenomena, and I am unsure if this is the right methodology for this research question. Is it only a phenomenon for me? What if clinicians don’t see it as a phenomenon? Why do patients report it as a significant event? A single event? (Journal entry, 12 June 2013).

Again, in the following journal extract I was projecting my own sense of disclosure as an intimate process, perhaps as I had experienced it with my father, on to the research agenda:

The thing that has intrigued me for so long with this issue is a sense of intimacy that I get from considering being witness to someone on their journey to death entering this space with a patient that is exclusive and so othering. Yes, we are all going to die but no one can know what it feels like to be told unless it is happening to them (Journal entry, 19 June 2013).

I used the discipline of writing a journal initially to try to identify and bracket off assumptions such as this, particularly prior to interviews and immediately following them. I found it helpful to journal these thoughts, not to counter them but to identify their potential to impact on the research process

and situate them within this “hermeneutic circle” (Smith, Larkin, and Flowers 2009, p. 35). The following journal extract provides a good example of this:

Dr X moved directly and quickly into recalling her first experience with a dying patient as a student nurse and in the telling of this story her Christian faith was declared. It was unexpected and I was unsure if this was something she may have expected me to share given my connection with her niece. I now wonder if perhaps I could have pursued this but clearly felt compelled not to engage with this in the interview perhaps some fear on my part early into the interview that I didn’t know what I was engaging with also wondered if this was testing my response, would it be assumed that a fellow Christian would respond differently (Journal entry, 8 April, 2014).

IPA emphasises what is referred to as a “double hermeneutic”; that is essentially a two stage interpretation “as the participants are trying to make sense of their world; the researcher is trying to make sense of the participants trying to make sense of their world” (Smith et al. 2009, p. 53). At times this spiralled into a helix of sense-making of my sense-making of the research participants’ sense-making:

It seems the diagnoses process provides the mechanism for interpreting and making sense of experiences of patients and clinician’s responses to that. The clinician is making sense of the patient’s sense-making through a diagnosis process and the patient is re-making sense from the clinician’s sense-making and is renegotiating/continually re-establishing own sense of self/security. I am making-sense of their sense-making of this (Journal entry, 10 July, 2014).

Finally, the reflexive process of journaling was helpful throughout the research process but came to the fore as a link back to the research process following disruption and in the shift to narrative analysis. Recording the challenges I experienced in the research facilitated an understanding of the methodological issues I faced; at times acting as the missing pieces in the puzzle in my own research narrative.

## Analysis

### IPA Analysis

The process of IPA analysis outlined by Smith, Larkin, and Flowers (2009) was used to guide how I analysed the data gathered. Drawing on a phenomenological perspective, I wanted to understand what it is like from the

consultants' point of view; specifically what it means 'to take their side' and also simultaneously work with the data to critically examine what is going on that the research participant may not be consciously aware of (Smith, Larkin, and Flowers 2009, p. 36). The IPA researcher is encouraged to take another stance, this time stepping outside of the participant's shoes to stand to one side and question what is being said (Smith, Larkin, and Flowers 2009, p. 36).

I focused on identifying themes from the data to give voice to each consultant's experience of this phenomenon. A "detailed case-by-case analysis of individual transcripts" was conducted, commencing with a preliminary analysis of the first interview transcript through reading, listening and re-reading the transcript many times to become deeply familiar with the research participant's account and ensure their voice was present with each reading (Smith, Larkin, and Flowers 2009, p. 55). Alongside this process I continued to reflect on my responses to the transcripts that may be influencing the analysis:

I am not sure if I am coding things under the right categories of linguistic, descriptive and conceptual. I find myself reacting personally to things I am reading, particularly when I hear them as egotistical or paternalistic. I know this is my influence on the script. I need to put that aside and really try to hear what he is saying is important to him (Journal entry, 2 April, 2014).

On the second and subsequent readings coding or "initial noting" of descriptive and linguistic comments was sequentially entered in columns adjacent to the text (Smith, Larkin, and Flowers 2009, p. 88). This was followed by a shift to the interpretative process of "conceptual coding" that Smith, Larkin, and Flowers (2009, p. 88) describes as "a move away from the explicit claims of the participant ... toward the participant's overarching understanding of the matters that they are discussing". Again, my journal entry reflects the shift this process fostered in my analysis from the example above:

I am hearing more of what it is to be him rather than how it is for me to listen to him (Journal entry, 14 April, 2014).

The preliminary analysis was then abstracted and clustered into high level themes representing meaningful units relevant to the research focus (Smith et al. 2009).

Approaching this method of analysis for the first time I found the suggestions for physically cutting and sorting themes on pieces of paper and assembling them in large envelopes unusual but because I was new to IPA I decided to try this hands-on method. With themes written on paper stuck to walls, arranged, revised, assumptions tested and revised again, the depth of data and power of the interpretative analysis of that data became apparent. Looking for relationships across themes became a creative endeavour through

the act of interpreting and identifying connections, then rearranging themes to identify insights into other levels of possible meanings. In part, that creativity was facilitated by what Larkin, Watts, and Clifton (2006, p. 114) describe as IPA's "epistemological openness" that allows the researcher to draw upon a considerable 'interpretative range'. This range encourages the researcher to "explore and innovate in terms of organizing the analysis" that opens up multiple possibilities for interpreting and drawing out meaning (Smith, Larkin, and Flowers 2009, p. 96). I drew on discursive, temporal and cultural elements as well as looking for patterns in frequency of repetition to try to push beyond the antecedent descriptive stage (Smith, Larkin, and Flowers 2009, p. 98).

Continuing the analysis of single transcripts in isolation of each other proved challenging as there was a strong tendency to want to identify patterns between interview data. To mitigate the risk that prematurely conceptualising themes across each transcript might result in overlooking critical data I staged each transcript analysis with interviewing, transcribing and writing.

The end result of this stage was five large envelopes; one for each interview, with a list of themes pasted on the front spread across a large table to commence the next stage of looking for connections across the interviews. Smith, Larkin, and Flowers (2009, p. 96) encourage the researcher to "eye-ball" lists of themes suggesting that "some themes will act as magnets, pulling other themes towards the". Walking around the table seeing the themes as a whole body of data for the first time; some connections were more immediately apparent whereas others did repel, seemingly polarised. As this process of analysis evolved new themes were added to a tentative master table of themes and then successive themes modified, developed and combined into categories. This produced an awareness of what had come before to an extent that "convergences and divergences" from these themes became apparent in subsequent transcripts (Smith, Larkin, and Flowers 2009, p. 73).

To ensure interpretations were valid I implemented a continuous process of comparing themes and categories across transcripts (Smith et al. 2009). This iterative process also required checking my own "sense-making" against what the research participant had actually said (Smith, Larkin, and Flowers 2009, p. 72). When the detailed analysis was completed, a process of prioritising the themes followed to inform the construction of the final table of 'super-ordinate themes' with related themes and excerpts from participants 'nested' under them (Smith, Larkin, and Flowers 2009, p. 101). These themes were then used to develop an emergent thematic analysis to inform the expansion of the analysis for the writing phase (Smith, Larkin, and Flowers 2009).

Smith, Larkin, and Flowers (2009, p. 36), draw on Ricoeur's interpretative position as an example of a double hermeneutic operating in IPA that required moving beyond empathetically "representing what the participant would say" toward a hermeneutics of suspicion to take a look at them from "another angle". The thematic analysis I had developed did not seem to do this and I felt I lacked the ability to find IPA's middle ground of a hermeneutics of



questioning to extend my analysis of what the consultants were saying (Smith, Larkin, and Flowers 2009, p. 36).

I returned to the literature on IPA and read a paper by Prunella Gee, a PhD candidate supervised by Jonathon Smith, one of the authors of the text on IPA I had followed (Gee 2011). Documenting the process of following the methodological steps outlined in the text to her study of male retirement patterns, Gee's experiences provided a pragmatic example. Her commitment to thoroughness in the analysis process and recommendation to first time users to follow the road map in the book "because it lays bare the skeleton" to identifying emergent themes renewed my resolve to keep analysing (Gee 2011, p. 21). This is evident in an extract from my journal where I thought I needed to uncover what was unknowable even to the research participant:

This is possibly what I was battling in the interview to get beyond this confidence, find a crack, something that revealed self-doubt or moments where his convictions failed him (Journal entry, 20 April, 2014).

In fear of being too descriptive and failing to bring forth the deeper meanings from what the consultants had said of their experiences I moved the interpretation further away from empathy trying to emulate a psychological interpretation of the consultants' experiences.

### **A Shift in Supervision and Analytical Framework**

I felt increasingly out of my depth and at my supervisors' suggestion, tried writing a case study descriptively and interpretatively. I lost my way only to discover I was still making too many assumptions and somewhat pejoratively. When I tried again with greater empathy, the feedback was I had lost interpretation.

With a change in supervision I came to understand the methodological limitations of applying IPA to this research question. Crucially, I realised my attempts to get an insider perspective with a small sample of medical professionals adept at managing people entering their world were highly unlikely to succeed. Why would they tell me, an outsider, in a fleetingly brief encounter, their innermost thoughts? Reconciling this limitation helped ease the sense of failure I experienced with the data I had generated and the subsequent analysis.

### **Symbolic Interactionism**

Given IPA has symbolic interactionism in its roots, I was encouraged to consider the thematic analysis from this perspective. Switching the framework for analysis from IPA to symbolic interactionism addressed the pressure I felt

to present an insider's perspective and as a result I began to build confidence in the themes I had originally identified.

I returned to the transcripts, this time captivated by the stories of disclosure experiences some of the consultants had shared with me. Reading Plummer (1995, p. 23) view of stories as the interactions between the "producers" (tellers) and "consumers" (listeners, audiences, readers) told in different ways in different contexts, gave me the confidence to work with the stories I had.

He poses several questions to consider in the sociological analysis of stories, challenging analysis to move beyond the focus on the formal structure of text to consider the social role of stories (Plummer 1995, p. 19). Like Plummer (1995) I was interested in why I was told a particular story, how the story was told, the strategy of the story teller, for instance in managing impressions and the link between the story and wider social context where these stories may perpetuate dominant discourses of medical professionalism.

Atkinson (1997, p. 328) points to the "centrality of narrative" to the culture of medicine, highlighting the significance of a wide range of medical narratives, from case studies and patient records to the tradition of narrating orally medical instruction and opinion. He suggests "telling the case is a powerful mechanism for enactment of professional work" and takes place repeatedly in daily medical practice as doctors engage with colleagues, formally and informally to discuss patients (Atkinson 1997, p. 328). The consultants' stories provided access to understanding how their meaning-making of the disclosure to a patient is constructed and interpreted through medical socialisation. Stories are often valued for their uniqueness and rarity and who tells the story in medical culture is hierarchically determined revealing how power is perpetuated as Atkinson (1997, p. 329) judiciously suggests:

*"Senior physicians have reserved rights to tell particular kinds of stories ... to tell personal stories of professional experience and can claim the floor to do so before an audience of peers and juniors."*

In medicine, doctors also tell their patients' stories in presentations, case histories and other narrative performances (Atkinson 1997). The confidence and skill in recalling detailed stories was a feature of the consultants' narratives. This led me to Goffman's (1959) dramaturgical analysis of social interaction as a performance and the medical encounter with their patient the "front stage" for disclosing a life-limiting diagnosis.

Clinicians are expected to perform in specific ways that are socially congruent with ascribed understandings in medical culture. Therefore the presentation of a diagnosis to their patients is a performance of each clinician's interpretation of 'doing' medical professionalism. They must deliver the presentation with the authority required for the patient to accept the diagnosis as legitimate to ensure the treatment and care they can offer will be followed.

In this respect the consultants' narratives of their disclosure of a life-limiting diagnosis to a patient can be considered as the site where identities, roles and responsibilities are created, negotiated and managed (Lehn and Gibson 2011).

At the same time I read Arthur Frank's (2004) book, *The renewal of generosity: illness, medicine, and how to live*. Here I found themes of demoralisation and the transformation to caring relationships through generosity that resonated with some of the consultants' stories. I was able to reconnect empathetically with the consultants' experiences. I could hear stories of resistance, when generosity had been extended despite professional pressure, and shift from a psychological analysis of personality type to a social analysis of the impact of medical socialisation, norms and expectations on the consultants' experiences.

Drawing on Foucault, Holstein and Gubrium (2009, p. 162), describe a "disciplinary gaze" as a particular way of seeing the world which results in "characteristic narratives, leading participants to story things in special ways". Through the consultants' "disciplinary gaze" their narratives of the disclosure of a life-limiting illness to a patient was embedded within, and informed by, the culture of medicine (Holstein and Gubrium 2009, p. 162). Initially I had interpreted the response from some consultants to the question of when they "tell" as deliberately obtuse and one of my early themes was "*Where is the telling?*" When I reconsidered this in the context of the characteristics of disciplinary narratives I could understand the importance of locating the disclosure experience within the temporal trajectory of a patient's illness and the consultant's own position in the structures of organisational health care to their meaning-making.

In this way, the analysis of consultants' experiences shifted from the psychological to the social, cultural and professional context in which they, and I, came to understand the disclosure experience.

### **Narrative Analysis of the Clinicians' Perspectives**

Although there is much debate over what a narrative is, I have, like Riessman (2008, p. 7), used the term interchangeably with *story*, to mean the first-person account of the consultants' experiences of disclosure. Locating narratives in research interviews is not uncommon as respondents will sometimes order their experiences into long stories (Riessman 1993, p. 3). However, stories told in interviews are not always clearly demarcated with more commonly used "entrance and exit talk" such as "that reminds me of a story" (Riessman 1993, p. 17). The issue for the researcher is deciding where the narrative begins and ends.

Exploring the typology of narrative analysis to identify how I should make this decision I looked to Riessman (1993, 2008) who provides theoretical and practical guidance building on the work of Gee (1986) and Gee (1991), Mishler (1986) and William and Waletzky (1967). Riessman emphasises there is "no

one method” she uses in narrative analysis and encourages a blurring of the boundaries to look not just at the linguistic form of texts and the thematic content but how, and why, the respondent selected this story and organised it in this way (Riessman 1993, p. 5).

The process of narrative analysis is slow and painstaking “requiring attention to subtlety: nuances of language, audience, organisation of text, local contexts of production, and the circulating discourses that influence what can be narrated, and how” (Riessman 2008, p. 18). Interestingly, Smith, Larkin, and Flowers (2009, p. 106) claim a “strong intellectual connection with various forms of narrative analysis” and cite Riessman’s work as an example of the shared emphasis on the personal and meaning-making through the analysis of the lived experience and relationship to personal identity in the telling of a story. In this respect I was able to draw on the themes I had identified in the IPA analysis that emerged from the linguistic, temporal and contextual coding of individual transcripts.

For example, initial readings of the data I had gathered appeared dominated by the process of diagnostic actions. I had written of this in my research journal though had discarded this as too descriptive in later analysis:

There has been something in the tone of each interview that has felt like a clinical synopsis/description and I haven’t been able to fully identify what that is other than referencing Mischler’s “voice of medicine” - clipped and rapid intonation with a sense of listing things off and a need to get numbers, dates, times, actions identified quite explicitly. Perhaps the consultants I am interviewing are responding to and interpreting the research question as a problem, requiring diagnosis (Journal entry, 16 April, 2014).

Returning to the diagnosis process I began extracting excerpts from often long narratives and informed by Gee’s (1986) poetic representation of language, broke each story into parts. When I broke the stories into stanza-like forms of only a few lines each, other readings and interpretations emerged.

I then worked from Riessman’s (1993) process to look at how each story was organised using Labov’s (quoted in Riessman, 1993) framework of narrative analysis. This process involved identifying elements Labov considers part of a well-formed story including:

Abstract – an initial clause in a story that summarises what is to follow

Orientation – provides information on time, place, characters

Complicating Action – sequence of events

Evaluation – significance and meaning of the action, attitude of the narrator

Resolution – what finally happened

Coda – returns the narrative to the time of speaking

Not all of the stories had these elements and I was concerned this rendered the selection of narratives flawed. Riessman (1993) however, counters Labov's claims of the function of these elements to a story, suggesting there are few rules for partitioning parts of interviews that "feel like narrativizations" (p. 60). I was heartened by this and able to move on to look beyond the structure to question why the stories were told the way they were, what discourses they drew on and what the story was seeking to accomplish.

Deciding which stories to select, where to break the story into parts and in some instances, deciding where to end the story made my interaction with the text visible. I was conscious that extracting the clinicians' stories from the wider narrative risked isolating the meaning from the context of the conversation. To re-situate the excerpts I provided either a brief synopsis of the question and context that each clinician was responding to or included my voice in the text.

Employing this hybrid of narrative analysis styles I was able to work dynamically, shifting attention between the structure of the story, to particular linguistic features, such as verb tense, key words, repetitions, hesitations and turns of phrase and then to the broader social context.

In this way, I was alerted to both the form and the content of the consultants' stories and could abstract themes while preserving the narrative detail (Riessman, 2008). From this analysis the consultants' experiences of disclosing a life-limiting illness or prognosis to their patients emerged as more than just 'telling bad news.'

## Methodological Considerations

### Limits to Accessing Clinician's Inner Worlds

Larkin, Watts, and Clifton (2006, p. 104) highlight the potential difficulties inherent in the IPA researcher seeking to offer an 'insider's perspective' agreeing with Smith (2006) that access to the participants experience "is both partial and complex". Access, according to Smith, Larkin, and Flowers (2009, p. 53) "depends on, and is complicated by, the researcher's own conceptions; that are necessary to "make sense of that other personal world".

In many ways I had set myself up to fail. Clinicians learn how to manage their emotions, present themselves as empathetic, and to protect their patients from any overtly emotional responses they may have. I had no more right to accessing their inner worlds than their patients yet I had expected to gain entry.

Although I had indicated and prepared for 60–90 minute interviews, in the first interview I felt I had lost control and did not know how to keep the

interview on track. The following excerpt from the transcript illustrates the types of tensions that emerged:

*“Jo: For you though, that role though of being the doctors in end of life care, moving from that role of curing to not being able to heal ...*

*Dr K: Well it’s interesting because cure would be the medical word for making the cancer or disease go away. Heal, and there’s lots of literature, people will feel healed even though they’re dying. There’s a great gospel song Maryann Williams, “When the doctor gives up the healing begins”, that’s the lyric. So the word heal is actually has a much, much, more broader meaning. It doesn’t necessarily mean cure or even live. So that will come out in your literature.*

*Jo: Yes*

*Dr K: If it hasn’t, you’ll find that that word ‘heal’, people will feel healed if they’re dying.*

*Jo: Though interesting that lyric is when the doctor gives up?*

*Dr K: The healing begins*

*Jo: Where does that leave you as a doctor?*

*Dr K: Well it’s another one of the things when I’m teaching about communication to junior doctors there’s a few things I really talk about. If you mean death say death ...”*

I expected I could, with enough time and a flexible structure, encourage participants to reveal their innermost thoughts about their experiences to me. This assumption that research participants’ inner-most private experiences can be accessed during an interview is challenged by Atkinson (1997, p. 327) in his critique of research where narratives are regarded as “offering privileged access to personal experience”. Furthermore, the assumption in IPA that what participants say of their experience provides insights into their “psychological worlds” led me away from the socio-cultural contexts of these experiences (Todorova 2011, p. 37). Although there have been calls to include these contexts in IPA analysis, I believe the considerable skill and experienced guidance required is a barrier for a master’s thesis (Todorova 2011).

### **Power and Positionality ‘Interviewing Up’**

Perhaps another limitation to using IPA as an early researcher was the pressure experienced interviewing a small number of participants. It seemed there was little room for error with only four to six participants to interview and yet I had no previous experience conducting social science research interviews. This pressure was exacerbated by the thought of entering the world of senior

medical professionals and asking them to talk openly about potentially difficult, troubling and personal experiences.

I was unprepared for the negotiation of power and my overall sense of powerlessness in the interview process. To say that I overcame this would be untrue, however, I did adjust by using this pressure to prepare well, listen intensely and tap into the assumptions I was bringing to the process through journaling and in discussions with my supervisors:

I felt there was no research question to be answered, it felt irrational, wrong to be asking, prying into a closed world; “we have this sorted.” Of course why did I think any differently, how else can you do this job? (Journal entry, 15 March, 2015).

In some ways it also eased my apprehension that the first interview secured through the recruitment process was with a medical practitioner who was known to me. Similarly, the second interview I conducted was with a consultant I knew personally. However, knowing the research participants brought other challenges as I was conscious of the shift from social conversation to a more one-sided narrative that needed to occur and mindful in that process that I was probing into aspects of their lives not previously disclosed. Contrasted with subsequent interviews where I had no previous connection to the participant, the negotiation of roles was more pronounced.

Frequently reference was made to the literature on various subjects and statistical data related to outcomes, treatments, prognosis and patients. This left me wondering where I was placed by the participants who were all successfully positioned in the hierarchical organisation of medicine and for some, also academia.

Reflecting on my journal entries I was aware that questioning my positioning in this context manifests my own preconceptions and latent beliefs that ascribe status to medical professionals, in particular consultants, because their work saving lives is more important:

Conducted the fourth interview today and I still feel unsure I have gathered what I expected to, or what I need. The interview was at the hospital and again this context made me very aware of the limited time the consultant had available and the other, more pressing and important demands on them. Am I just overly sensitive to this? It brought into question my legitimacy researching medicine from outside of the institution and in addition, wanting to traverse territory that is quite possibly well-hidden even inside the institution (Journal entry, 30 April, 2014).

Along with the tellers or performers of stories, Plummer (1995, p. 21) identifies the “coaxers, coaches and coercers” who “probe, interview, and

interrogate”. Doctors are one example, as are social researchers. Then there are the consumers, readers and listeners who interpret and make sense of the stories.

In these interviews I was coaxing the ‘coaxer’ and also the audience consuming the story. I was aware of occupying multiple roles in constructing the stories that emerged. The power dynamics shifted accordingly. I had little control over where and when interviews took place, how I was positioned by the consultants’ and how this determined how they would answer the questions I asked.

However through the analysis process the power I had to interpret and represent the consultants’ experiences was marked and at times, disconcerting. This experience was eloquently articulated in the following excerpt from Plummer (1995, p. 21):

*“Sometimes people hear so lightly what others say so intensely, and sometimes people hear so intensely what others say so lightly.”*

During the analysis process I questioned if what I had heard intensely, for example in the stories of the diagnosis process, was relevant to the disclosure experiences when for the consultants’ this was often presented as routine. Similarly I could see times when they were hearing intensely, as if on guard, to what I had said lightly as this transcript extract shows:

*“Jo: So when you are called in an advisory capacity are you there to manage the conversation with the patient and the family or has that already happened?”*

*Dr: Well, it depends. Can you clarify what you mean by “manage the conversation?””*

The experience of interviewing into this profession was challenging and at times, frustrating yet it has strengthened my resolve to pursue opportunities to continue research with clinicians. The barriers to entry are significant but I believe there is value in hearing their voice in qualitative research given the often negative representations of clinicians in much of the patient literature.

### **Outsider to the Medical Profession**

Clearly not an insider to the medical profession I had a more acute awareness of being distinctly outside of this population (Dwyer and Buckle 2009). I questioned if the experiences consultants shared would have been restrained, modified, or even withheld if there was a sense of ‘reputation’ or ongoing professional relationship to be considered. Equally, I am aware of, and have empathy for, the professional management of me as an ‘outsider’ to the consultants’ world.



Pragmatics determined the interviews were located in medical environments, often with unavoidable interruptions from phone calls and knocks at the door. When interviewing participants I knew personally, this environment facilitated a distinct and necessary boundary between social and professional worlds. It also sharply contextualised my position as a non-medical person who despite my own experiences of hospital care could not access the unique and complex, micro society of the hospital.

This experience generated insights into my role in relationship to the research participant from an insider/outsider perspective. Being outside of the medical profession was both an advantage and disadvantage. At times in an interview I wondered if some information was withheld or restrained because I was not identified by the participant as a medical professional with whom they may have a sense of a shared social reality that could engender professional trust. For example I would become aware of a hesitation when technical aspects of patient care were being referred to and at others, a flicker of frustration if I sought clarification on the way care was structured or pain relief was negotiated.

The second interview brought into question more acutely the credibility of researching from outside of the institution of medicine and using a qualitative, rather than a positivist/empirical approach that is common to medical research. This time I had to reorient to the person I knew socially as the person-in-their-context that favoured a clinical approach to their meaning-making of the diagnosis process.

Conversely, I considered the times I occupied an outsider status afforded insights that I may not have been sensitive too if I was researching from within. This was particularly apparent in my observations of the medical environments where all of the interviews were conducted and the way the participants interacted with their highly familiar territory. Stark differences were apparent in the public, private and hospice offices and waiting rooms, from the intensity of fluorescent lights highlighting blemished walls and battered metal furniture to bird-song both real and piped softening the harsh realities of the cancer embodied in the buildings. I waited alongside the patients and was greeted then ushered into an office or treatment room much as they would be. In all but one of the interviews, the room was furnished with a desk and adjacent to the desk, three chairs in a row from which I was invited to select one to sit in.

What appeared a routine and unremarkable practice presented immediate dilemmas for interviewing because it wasn't apparent that we could face each other whichever chair I selected. Also I needed proximity to place the audio recorder in position but if I sat too close would this assume an intensity or encroachment given I wanted to elicit fairly personal information in their 'professional' space? Equally, selecting a seat at the end of the row may indicate I was deliberately distancing myself from the participant. Each time I did end up selecting the seat closest to the desk though it never became

routine or comfortable and I frequently observed participants moving in to face me, or around to their desk, or further away, in tune with the information being shared and the questions I was asking.

Another advantage of researching from the outside was the latitude this granted to ask questions that may have been considered naive, ill-informed or confronting if I was a medical colleague. Unsurprisingly, this was easier for me with the participants that I had no previous connection with, although all of the research participants engaged deeply with the research questions in the interviews. This level of engagement was rewarding for an early researcher although access to their worlds was always limited by the power of the participants' position in relation to my own, as an outsider (Merriam et al. 2001).

## Limitations of the Research

### Disruption to the Research Process

With the progression of my father's illness I found I was researching an issue that was unexpectedly unfolding before me. I needed to reorient to the realities that research, like work, is managed in the context of everyday life and acknowledge that while I was an insider to the diagnosis process with my father, I was an outsider to what it meant to be the person diagnosed. Having conducted one interview and in the process of scheduling another, I knew that if I continued with the interviews there was a risk my quest to understand, prepare for and make-sense of, the personal vortex I had entered, would lead interviews off-course. I had already become *that* carer, referred to with disdain in the first and subsequent interviews I conducted, questing for information on all the wrong search engines and had unconsciously expanded my literature review to include end-stage prostate cancer. With my supervisors' guidance and support, I received approval to suspend study for four months. The disruption meant I lost some continuity in the recruitment phase and experienced an extended period of data collection.

### Sample Size and Bias

Limited access to the research participants and the constrictions on the time they had available was a barrier to including follow-up interviews in the research design. The analysis has been limited to data collected from single interviews only where repeated interviews may have facilitated an opportunity to develop a deeper knowledge of the participant and to test and refine the analysis.

The small sample size ( $n=5$ ) of the research project is a limitation to the generalisability of the research findings. Broader representation of gender, ethnicity, age and medical specialties was not possible in a small sample size

and therefore limited the analysis. Relying largely on a snowball method of recruitment meant the sample was strongly biased toward participants with professional interconnections. In some instances, the selection of participants was influenced by other participants identifying who they knew and/or who they thought would be a suitable research participant.

## Ethical Considerations

A formal application was prepared and submitted to the University of Canterbury Human Ethics Committee for approval. Preparing the application provided an opportunity to consider the potential ethical implications of this research and identify strategies to mitigate these. I prepared an information sheet and consent form as part of the application outlining the nature of the research, an indicative interview schedule of questions and the time required for the interview.

An important ethical consideration was the potential risk that research participants may experience some emotional distress because they would be engaging in a reflexive process about their professional experiences disclosing a terminal diagnosis. There existed the possibility that in some instances participants, when recalling experiences or specific situations with patients, may identify or reflect on aspects of the process that didn't go well. To manage this potential risk I ensured the information sheet clearly communicated the focus of the research interview so participants had time to gauge their comfort with the process and self-select on this basis. I also offered to meet or call to discuss the research in more detail so that participants could ask questions directly. Three participants who had been referred to me accepted this offer facilitating an additional stage to the consent process that allowed them to consider the research and the researcher independently of the recruitment process. These discussions were predominantly focused on the participant ascertaining the relevancy of their experiences to the research and the logistics of scheduling the interview.

Should participants have experienced distress in the interview, I planned to pause the interview and offer to re-continue or if required, re-scheduled the interview when the research participant was ready. However in all of the interviews it was apparent that the participants had considered the issues and their experiences beforehand; selecting anecdotes that were reflective but not deeply distressful.

Confidentiality was another significant ethical consideration with this research notably because of the small research sample and cohort. New Zealand is a relatively small country with a correspondingly small number of medical specialists and as such, identities of research participants may have been more readily identifiable. Assuring participants of confidentiality in this context was paramount to ensuring participants were confident that they could

disclose any information about their experiences without perceiving the process could harm their individual professional standing and more broadly the medical profession. To achieve confidentiality all potential identifiers were removed from the research including names, references to family members, geographical location, specific medical speciality and place of employment. Furthermore, any anecdotal references to patients, their families and other health professionals used to illustrate the participant's experiences, were also removed. Returning the interview transcriptions to the participants to review also allowed time to redress any topics covered and withdraw any information. Participants were advised of their right to withdraw from the research at any time providing an additional mitigation strategy should participants experience discomfort with the interview or reviewing the transcription.

Electing to research in an aspect of end-of-life care that was germane to my life also presented ethical concerns in terms of the risk I could experience personal distress hearing the information and experiences consultants recounted in the interviews. Not only would this be distressing for the participants if I was noticeably upset during an interview, it may manifest more subtly impacting the ability to establish an appropriate research relationship. These risks were discussed with my supervisors at the formative stages of the research and meetings were scheduled prior to interviews, allowing time to reflect and prepare. Simultaneously, the journaling process was employed to foster a self-reflexive process to identify less discernible issues. These strategies were highly effective and along with the decision to suspend studying minimised the risk of personal harm.

## Conclusion

I embarked on a research project with expectations of getting participants to reveal to me, and possibly for the first time, themselves, deeply personal revelations of their experiences. While I can reflect on this at the conclusion of the journey and question my naivety, I can see that my starting point facilitated the most significant learning in the thesis process. Perhaps because I learn best by doing I had struggled to connect with methodological course material. Daunted by the myriad of approaches and over eager to get on with the business of doing research, I hoped to figure things out as I went along.

Consequently, I have faced numerous methodological challenges. I have also learnt first-hand that social research does not happen in a vacuum and while challenging on many levels, it has been integral to developing an understanding of both the practice and theory of learning what it means to engage in qualitative research. It is from these experiences; pivotal to my research journey and the research findings presented in the following chapters, that I have positioned and informed my approach to the thesis.

## Chapter 4

# Literature Review

### Introduction

There is a largely critical body of literature detailing negative patient and allied health professionals' experiences and perceptions of truth-telling (Parker et al. 2001; Schofield et al. 2001; Salander 2002; Schofield et al. 2006). Situated within a complex realm of narratives in the literature that both glorify and demonise the medical profession, the physician is asked to negotiate the pre-conceptions and expectations of the patient to deliver a message that confirms their death is imminent. The clinical encounter is viewed by Charon (2001, p. 1900) as the site of a complex interplay of individual needs and socially constructed responses where "granting tonic authority to its physicians while regarding them with chronic suspicion, the public commands physicians to understand and treat disease while doing no harm."

To understand the practice of disclosure by physicians with their patients I begin with the wider shifts in cultural and social expectations of medicine's management of death and dying. What emerges from the literature is the practice and processes of disclosure cannot always be considered as distinct acts of telling the truth or not. With the social and cultural expectations that it is the physician who is responsible for the disclosure of a diagnosis or prognosis, it remains in their remit to judge what to say and when. As a consequence, the influence of medical culture on how the responsibility of disclosure is interpreted, managed and enacted by physicians is integral to this analysis.

The influence of medical culture on physicians' experience of disclosure is followed by a discussion of the process and experience of disclosure as a single moment of telling or occurring over a longer process. Diagnosis is the critical process of the disclosure of a terminal diagnosis or poor prognosis. The processes involved in reaching a terminal diagnosis is managed within the structure of medical specialities. This can mean for some physicians there will be longer therapeutic relationships with their patients while for other physi-

cians, the relationship will cease when curative treatment is no longer possible. For both the physician and the patient, disclosure processes are shaped by the organisation of medical care and this can mediate as well as exacerbate their respective emotional responses and adjustment to the diagnosis or prognosis.

Physicians' experiences of disclosing a terminal diagnosis or poor prognosis to their charges has been underresearched, despite ongoing calls for such research to be done (Klenow and Youngs 1987; Dickson et al. 2002; Grassi et al. 2000). In addition much of the physician situated research is generated from quantitatively orientated perspectives such as surveys and as such the physician's voice is largely unheard (Dickinson and Tournier 1994; Dickson et al. 2002; Dimoska et al. 2008). Drawing on the literature that considers the potential impact on physicians of working with patients who are dying and the disclosure process, I then look at how this can translate into what Frank (2004, p. 86) Frank refers to as a "demoralization of medicine".

## Too Tell or Not to Tell

Although over time the preference for open-disclosure has become wide-spread in western societies, the practice of full disclosure is less distinct. In this section I argue that framing disclosure as truth-telling or lying over-simplifies this nuanced and complex process. Disclosure does not occur in a "cultural vacuum" and needs to be considered in a broader context of social and cultural influences to understand why physicians may choose to manage how much a patient is told and when. I consider the historical, technological and demographic changes influencing the shifting boundaries of death and dying. Alongside these changes social scripts of ideal deaths have emerged. Troubled by an increased reliance on medicine and the moral imperative to preserve the sanctity of life at all costs, I conclude from the literature that boundaries of truth-telling in disclosure are not always indubitable.

## Historical Shifts Influencing the Disclosure of Dying in Western Societies

The decision to disclose a terminal diagnosis or prognosis to a patient, has plagued medicine for centuries and has been the subject of philosophical, moral and ethical debates that Sokol (2006a, p. 632) suggests frequently position doctors as the "masters of equivocation". In his historical analysis of the shift in medicine in western society<sup>1</sup>. Sokol (2006a, p. 632) asserts the disclosure

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<sup>1</sup>Though the focus of this research is practices of disclosure in a western society, there is a body of literature referencing the cultural differences in disclosure preferences and practices (Sokol 2006a; Wood, McCabe, and Goldberg 2009; Zier et al. 2012; Carrion 2010; Martis and Westhues 2013; Arbabi et al. 2014) including China and America (Xue, Wheeler, and Abernethy 2011), Asian patients in New Zealand hospital settings (Windsor et al. 2008) and older people with a later-life disability in the US (Ahalt et al. 2012). However Nie

of a terminal diagnosis or prognosis remains a contentious issue with many of the ethical considerations for and against “benignly intended deception” as relevant to the debate today as it was centuries ago. The ethos of preventing harm that underlies this discourse of medical care is applied by proponents on both sides of the disclosure versus non-disclosure debate.

Some of the literature on the disclosure debate references its genesis to the time of Hippocrates in 400BC who wrote of his concerns to physicians about the risk that patients will “take a turn for the worse” if told their illness would result in death (Krisman-Scott 2000; Sokol 2006a, p. 48). The practice of concealing the prognosis to patients was widespread throughout the nineteenth and early twentieth century though, according to Krisman-Scott (2000, pp. 48–49), some physicians had begun experimenting and reporting on their positive experiences with truth-telling to their patient.

The shift toward more open disclosure in predominately western societies decades later is discussed in the literature with reference to numerous surveys of patients and physicians during the 1950s and 1960s (Field and Copp 1999; Krisman-Scott 2000; Gordon and Daugherty 2003; Sokol 2006a). Data generated from patient surveys conducted in the 1960s in the United States indicated an overwhelming support for full disclosure of information; however surveys of physicians at the same time were less consistent (Krisman-Scott 2000; Sokol 2006a). Some physicians reported lying to the patient about their prognosis in the terminal stages of cancer, in contrast to the results of another study where the majority of surgeons disclosed a full account of the cancer diagnosis (Krisman-Scott 2000; Sokol 2006a).

Sociologically, the work of Glaser and Strauss (1965) on awareness contexts and dying trajectories reflects the growing interest in death and dying in academic research at this time. Focusing on interactions with dying patients and medical practitioners where there was a practice of non-disclosure, Glaser and Strauss (1965, p. 64) identified ways patients and medical staff engaged in what they termed the “ritual drama of mutual pretense”. The tactics employed by staff to hide the truth and counter tactics used by patients to try to uncover information identified tensions and difficulties for both the dying patient and those caring for them when the truth was withheld (Glaser and Strauss 1965; Timmermans 1994; Sokol 2006b).

Likewise, many attribute Kubler-Ross’s (1969) work on the articulation of five psychological stages of dying that followed Glaser and Strauss, as a powerful influence on prescribing new norms of death and dying (Timmermans 1994; Seale 1998; Seale 1995; Seale 2000; Craib 2003; Seale and Geest 2004; Timmermans 2005; Kaufman and Morgan 2005; Charo Rodríguez et al. 2011). The work of Kubler-Ross (1969) on the stages of grieving situated the

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(2011), counsels against dichotomizing east and west cultural differences in bioethics which oversimplify and hide cultural pluralities. He argues against the sociological assumption of a tradition of non-disclosure in Chinese medical practice and cites studies indicating a strong preference from patients for knowing the truth.

disclosure of a terminal diagnosis and prognosis to the patient as a critical determinant toward the pathway of achieving a ‘good’ death. Full awareness of impending death facilitated time for the patient to make sense of their death and engage in shaping how their terminal phase is managed (Seale 1995; Field 1996). Medical practitioners who do not openly and directly disclose a terminal diagnosis to their patient could be positioned through this lens as doing grave harm by denying the patient the opportunity to prepare for a good death.

The trend towards open awareness of terminal diagnosis since the 1960s also parallels unprecedented technological advances in medicine. With ageing populations increasing, along with life expectancies, end of life treatment decisions are diffusing into a broader range of medical disciplines and frequently complicated by existing co-morbidities e.g. renal dialysis treatment for an older person with dementia (Grönlund, Dahlqvist, and Söderberg 2011).

Shifts in technological advances that evolve into new medical specialties mean the scope of specialties are further refined and narrowed by higher levels of specificity, for example oncologists that specialise in surgical oncology or radiation oncology (Detsky, Gauthier, and Fuchs 2012). The impact of specialisation can mean multiple physicians can be engaged in the disclosure process with a patient. Detsky, Gauthier, and Fuchs (2012) highlight how specialisation can mean the patient is seen less as a whole person as they become compartmentalised relative to the specialty. Good (1994, p. 80) offers a more global description of the impact on both the patient and medical practice where disease is now the “object” and the person is the site of the disease. No longer the “narrative agent” the focus has shifted away from the patient’s world to what has become known as “routine, rational medical practice” (Good 1994, p. 80). Here, the patients’ experiences of their illness are often subordinate to the physical manifestations of the disease and become the singular focus of the diagnosis process.

### **Shifting Boundaries of Death**

Seale (2000) attributes the effect of these technological, demographic and epidemiological shifts to a constantly shifting definition between potentially treatable to no-longer treatable conditions. For example, a diagnosis of cancer still typically scares people, but with the increase in successful treatments it is no longer considered synonymous with a terminal diagnosis (Seale 2000). Impending death, when it is determined by a diagnosis, is in some instances able to be a controlled and possibly slow death (Krisman-Scott 2000; Seale 2000).

Sokol (2006a) claims the shift in cancer disclosure is less attributable to ideological changes on the part of physicians and more because of medical advances in diagnosing and treating cancer from the 1950s onwards. Others concur, arguing rapid medical advances have offered greater power to change the conditions of dying and increased the range of options clinicians can offer



patients to treat potentially life-limiting illnesses (Callahan 1993; Field and Copp 1999). With more options available for treating pain and the disease processes of terminal illnesses Field (1996) argues more medical practitioners are willing to talk openly with patients about their diagnosis and prognosis. In effect, rarely is there nothing more that can be done for the patient. Even if curative intent is no longer possible, physicians can refer patients to palliative specialists where a further range of palliative treatments become available. Schofield et al. (2006) see this as a consequence of the increasing effectiveness of medical intervention in that the disclosure conversation can be mediated and softened with an extension of treatment options used in a palliative sense, moving from cure to symptom control for as long as possible. They describe this as a blurring of the traditionally “sharp transition point” from curative to palliative care (Schofield et al. 2006, p. 398).

Timmermans (2005) points out that palliation becomes quasi-curative with the use of hormone treatments, radiotherapy and chemotherapy in some advanced cancers such as breast and prostate that can be used to delay death or keep it at bay. Correspondingly, constantly improving statistics of survival rates change the disclosure conversation. The expectation of a good prognosis from an initial cancer diagnosis maintains the focus on treatment options for the disease rather than the impact this has on the patient’s life.

Clinicians are able to draw on discourses from hopeful anecdotal and statistical evidence of other patients’ survival. Willig (2011, p. 899) draws on her own experiences being diagnosed with cancer, identifying how “military metaphors” are used, appealing to patients and professionals alike to fight the battle against disease “courageously and valiantly” to the end.

Craib (2003) also references the social and cultural scripts of dying that have emerged, presenting models of idealised dying such as the heroic and brave, living life to the full until the end, to the peacefully reconciled and orderly, good death. In all of these scripts lies the notion of death with dignity. Yet, Nuland (1994) in his book, *How We Die* reminds us the very act of dying requires letting go of control over physiological systems as a “series of destructive events that involve by their very nature the disintegration of the dying person’s humanity” [p. 17]. He suggests the dignified death discourse reinforces ideals of our own death, and the deaths of others we may witness and learn from as romanticised moments of cleanly and calmly, slipping away (Nuland 1994). The myth is perpetuated in our attempt to deal with the less comfortable reality that death is rarely dignified (Nuland 1994).

For some patients, the plethora of palliative treatment options available to where possible delay death may make the disclosure of a terminal diagnosis easier but also increase expectations that their dying trajectory will be slow. Schofield et al. (2006) caution new norms derived from the examples of other patients who go on for years, can be inadvertently set up as the optimistic message of a new hope; not a cure, but as many years as possible to death.

### Faith in Medicine for Salvation From Suffering

Lupton (2012, p. 7) reasons that in western societies trending toward increasing secularization and individualism, survival is increasingly dependent on medical progress and “faith in medicine is a creed”. Similarly, Good (1994, p. 86) attributes medicine with not only influencing what we have come to know as suffering but also as the mechanism for delivering salvation from that suffering. Good (1994, p. 86) develops the claim that in a civilization “deeply committed to biological individualism” the devotion to maintaining life and reduction of physical suffering have become paramount. The conflation of these widespread beliefs of human agency taming the powers of nature and an avowed sanctity for life produces a powerful mandate for physicians. Charged with salvaging life from death’s icy grip positions medicine and medical practitioners as the intermediaries between life and death in the literature (Good 1994; Nuland 1994; Callahan 2000).

According to Chapple (2010) this produces a moral imperative for patient and physician alike to preserve the sanctity of life against the enemy of death. Simply accepting death is considered to be a rejection of modern medicine and therefore a rejection of the value of human life (Chapple 2010). Good (1994) argues this translates into clinicians needing to act whenever they can and patients expected to accept their actions, in the medicalised fight to salvation. In doing so, Callahan (1993, p. 89) positions medical science as integral in distancing society from death by focusing attention single-mindedly on the causes of death and “fostering the illusion that mortality can be eliminated by eradicating lethal disease”.

This imperative for action underpins medical professionalism and to not act could risk legally and morally contravening the Hippocratic Oath. In the research for this thesis a key theme was physicians desire to preserve the patient’s hope and alleviate suffering. Even when patients were moments from death, physicians talked of intervening to lessen the symptoms of dying. To not intervene could be considered giving up and having nothing more to offer their patient, when they considered there was always something more that could be done. To this end, what we have come to know as natural death is medically managed as the good death; peaceful, pain free and welcomed when the time is right (Shim, Russ, and Kaufman 2006).

However, Callahan (2009) positions death in this context as contingent and isolated to the individual, such that the patient will die because of misfortune; a biological accident, or individual failing rather than as an inevitable outcome of being mortal. As a result the ongoing belief in the power of medical interventions is not threatened because death can be explained as individual and isolated events (Chapple 2010). Thus, Chapple (2010, p. 81) argues in a death denying society the contingent death of others provides distance from our own death; “it is a problem only for those immediately affected by it, rather than for the society at large”.

Furthermore, death remains controlled and contained within the medical paradigm. Timmermans (2005, p. 1000) argues the range of ideal deaths that has proliferated seemingly tailored to “specific dying situations” such as hospice care, sudden death, and even assisted suicide are “now firmly under medical control”. Managing the potential threat of new and alternative dying movements, he claims medicine “colonises” and absorbs competing scripts from these movements into orthodox practice; with the more “radical edges smoothed out” in the process (Timmermans 2005, p. 1000). Palliative care, as one example is often referred to as “a movement” informing an alternative ideology, with its attendant ethics and morality, on “how best to die” (McNamara 2004, p. 936). McNamara (2004, p. 936), views the hierarchy of care in palliative care organisations, where medical responses to the physical care of patients has prominence, as a way of offering “certainty and control to an uncertain process”. She concludes decisions practitioners made on whether to intervene or not in the patients’ dying are not only “rooted in science, but are overlaid with decidedly moral imperatives to change the circumstances of their patient’s lives, and ultimately, their deaths” (McNamara 2004, p. 936).

### **Blurred Boundaries of Truth-Telling**

In the literature on disclosure, the decision to withhold information from the patient of the extent of their illness is frequently referred to as lying (Grassi et al. 2000; Hagerty et al. 2005; Sweeny, Shepperd, and Han 2013). Telling, or not, becomes moralised as lying or truth-telling and the literature positions physicians as good or bad depending on what position is advocated (Sokol 2006b). However, other authors more generously see the physician’s hesitancy as a less sinister attempt to “soften the blow” and not take all hope away from the patient (Timmermans 2005, p. 152).

Alongside this, some authors challenge the notion of direct and full disclosure with arguments based on degrees of truth-telling (Hak, Koëter, and Wal 2000; Krisman-Scott 2000; Anderson, Kools, and Lyndon 2013). Running the gambit of outright lying to withholding some information or details about the future trajectory of the end of life process, it is suggested that some physicians may consider they are telling the truth, even though this has been somewhat modified or indirectly discussed (Miyaji 1993).

Lutfey and Maynard (1998) provide examples of an unspoken collusion to avoid talking of death directly from three episodes of doctor-patient interaction. Although the focus of the conversation was on the patient’s terminal illness and prognosis, the words ‘death’ or ‘dying’ were never used but only indirectly alluded to. Similarly, in a study conducted in 1997 of 365 American doctors predicting survival in 504 cancer patients the subtleties of telling begin to emerge. Here, it was found doctors withheld prognosis from a quarter of patients, and for the remainder were less likely to provide their own beliefs of

the actual prognosis, instead providing an overly optimistic estimate to many patients (Sokol 2006b, p. 635).

Timmermans (1994) sees this as a gradation of the awareness contexts originally provided in Glaser and Strauss's (1965) seminal work. In this context open awareness is distorted to an "uncertain open awareness" where clinicians remain the "gatekeepers" of information but hold back on the full account or soften the information to maintain the patient's sense of hope (Timmermans 1994, p. 332). Hodkinson (2013, p. 108) also looks at the blurred boundaries of truth-telling arising from the demands on the clinician to balance professional and legislated obligations to provide information to patients while ensuring patients are protected from harm and distress. However McNamara (2004) identifies another clinical situation where disclosure is potentially more complicated. Citing the hospice model ideal of the patient being openly aware of their dying, she identifies how palliative practitioners are increasingly challenged by discourses of patient autonomy and consumers of healthcare where patients can decide if, and how much they want to know. The decision to disclose a poor prognosis in this instance is removed from the physician but this can be difficult to negotiate when families and loved ones want to know and when seeking consent to treatment, particularly palliative sedation.

Some physicians also find it difficult to negotiate the transition from curative to palliative care. Broom et al. (2014) in their study of Australian medical specialists engaging patients in the referral to palliative care found broader social contexts for the variability in how this was negotiated. For many patients, palliative care was equated with imminent death and along with a loss of hope; they experienced a loss of the therapeutic relationship that had developed with the specialist (Broom et al. 2014). The process of referral had to be negotiated with care, patience and sensitivity in the context of uncertainty about how long their patient may live (Broom et al. 2014). A number of specialists spoke of the discussions as difficult and drawn out when they sought ways to minimise distress (Broom et al. 2014). Viewed in the context of specific patient biographies, some specialists cited examples of young patients dying as reasons for wanting to maintain treatment for as long as possible, particularly as young patients offered the greatest resistance to palliation (Broom et al. 2014). For many, tactics emphasising palliative care specialists as "more capable" were employed to assist patients and their families to come to terms with transition and get them the specialist palliative care needed to support them (Broom et al. 2014, p. 158).

The key issue germane to this research is the judgement lies with the clinician for whom the "burden of proof for the appropriate use of this privilege" still rests (Hodkinson 2013, p. 129). These debates bring into question how physicians experience the disclosure of a terminal illness in the context of expectations from society that the 'right' behaviour is to provide a direct and full disclosure and their professional ethos is to do no harm.

## Medical Culture

The process of professional socialisation as integral to the making of a doctor is articulated in a wide body of literature (Becker 1961; Haas and Shaffir 1982; Becker 1993). Medical students own agency in adopting, aspiring to, and constructing professional meanings of being a doctor is considered in the literature as part of the socialisation process (Charmaz and Olesen 1997; Kasket 2006b; Kasket 2006a; Arráez-Aybar, Castaño-Collado, and Casado-Morales 2008). The influence of medical culture and socialisation on how disclosure is enacted is integral to this thesis. Learning how to judge what to say to a patient, and when, I suggest, can be traced to the very first stages of medical education. Here, medical students learn and adopt strategies to appear competent as medical professionals. Managing their emotional responses to situations few lay people witness to ensure their clinical effectiveness is not compromised is critical. However, tensions can emerge with the all-consuming demands of medical practice, professional expectations and the needs of patients. Thus, examining the literature on medical culture situates the physicians' experiences of disclosure analysed in subsequent chapters within a powerful professional context.

## Medical Socialisation

Haas and Shaffir (1982) claim the process of successful socialisation to the medical profession is facilitated by a separation from the lay world. Drawing on Goffman's (1959) theories of impression management they argue learning the language of medicine, adopting medical scripts and wearing medical attire replete with tools of the trade separate the doctor from lay people and support the performance of appearing competent (Haas and Shaffir 1982). Developing a "cloak of competence" they claim, is all encompassing for medical students, co-opting their time, social lives and belief systems as they strive to deliver a convincing performance of their medical and professional competence (Haas and Shaffir 1982, p. 84). Facing the potential criticism, shame and embarrassment from their audience, be that patients, peers and/or senior clinicians, the pressure to appear competent is immense (Haas and Shaffir 1982).

Coined the "hidden curriculum" by Hafferty and Franks (1994, p. 865), the term refers to the medical training outside of the formal medical curriculum students are exposed to, in particular how explicit cultural and ethical values of right and wrong within the medical profession are internalised. Hafferty and Franks (1994, p. 865) consider the cultural influence on medical training that is in part a response to social and professional expectations that doctors will react differently to what they see and what they think, than lay people do.

From the cadaver dissection to the disdain from senior clinicians toward emotional involvement and expression, a number of authors have written about

how medical students learn to adopt strategies of emotional detachment to maintain neutral affectation (Parsons 1951; Hafferty and Franks 1994; Kasket 2006b; Arráez-Aybar, Castaño-Collado, and Casado-Morales 2008).

Parsons (1951) referred to the act of dissection as a rite of passage in medical training that he saw as not only a tool for learning anatomy but "...a symbolic act, highly charged with affective significance" that established young doctors relationship with death (Parsons 1951, p. 445). Patients are viewed as "victims of disease, objects for learning and subjects for research...transformed into objects of work and sources of frustration and antagonism" (Hafferty and Franks 1994, p.865).

Strategies of managing emotions to align with what is deemed professionally appropriate for the young doctor begin to emerge and can be seen at play in the disclosure of a terminal diagnosis or prognosis to a patient.

### Emotion Management Strategies

Shaw, Brown, and Dunn (2013, p. 247) suggest some doctors distance themselves from the patient through the presentation of biomedical information in order to block the patient's emotional response and avoid feeling uncomfortable themselves". In addition to communication skills, they identify other factors that contribute to how a clinician discloses a terminal diagnosis or prognosis including the emotional impact on them and how this may interact with their psychological characteristics and more broadly, their working conditions such as work-load and the structure of clinical care (Shaw, Brown, and Dunn 2013).

Results from their research supports the work of Loge, Kaasa, and Hytten (1997, p. 881) that "contrary to what many physicians believe, clinical communication skills do not reliably improve from more experiences". The reason for this is largely because some doctors rely on coping strategies formed very early in their medical training to reduce their own feelings of stress associated with early disclosure experiences with patients (Shaw, Brown, and Dunn 2013). Where these strategies have proved successful in reducing anxiety for the clinician, Shaw, Brown, and Dunn (2013), found they are likely to be adopted in the future, despite the potential negative impact on the patient. They also cite a "culture of invulnerability" many of the clinicians in their research referred to as influencing how they responded to the disclosure process (Shaw, Brown, and Dunn 2013, p. 245). In this culture doctors did not discuss their feelings with their colleagues and intellectualised the disclosure process to prevent any emotional experiences interfering with their objectivity, although some admitted doing this as a "self-preservation" technique to control their emotions (Shaw, Brown, and Dunn 2013, p. 246).

Hochschild (2003) in *The managed heart: commercialization of human feeling* identifies the characteristics of professions where workers are expected to provide emotional labour to generate particular emotions in others, par-

ticularly in service industries. She uses the example of flight attendants who are trained to control passengers' emotional responses to perceived danger, such as turbulence, by suppressing their own emotional reactions (Hochschild 2003). Medicine is another profession Hochschild (2003) identified requiring emotional labour. Patients seek comfort, care, support and understanding from medical professionals. Medical professionals are expected to respond empathetically to all patients and suppress their own emotional reactions to conform with patient and professional expectations (Hochschild 2003).

Drawing on the work of Hochschild (2003), Kasket (2006b) attributes the socialisation to medicine as a vocation as a key influence in how clinicians learn from the earliest moments of entering the profession the rules of emotion management. These rules are premised on putting the patient's needs first and ensuring they operated with clear-sighted clinical effectiveness (Kasket 2006b). Research suggests, clinicians' fear of losing control of their own feelings and fear of the reactions of patients and family when breaking bad news to terminally ill patients is sometimes a barrier to telling (Friedrichsen and Milberg 2006; Johansen et al. 2012). Kasket (2006b) identified strategies some doctors adopt such as selecting specialities where death is less likely to be encountered regularly, or deflecting their own feelings from the encounter through focusing on the patient's feelings or even blaming the patient in an effort to avoid emotional engagement.

### The Voice of Medicine

Barry et al. (2001, p. 479) draw on Elliot Mishler's concept of the "voice of medicine" used to describe the rational, purposeful and scientific attitude of the clinician reflected in conversations with patients that are dominated by medical interests. In contrast to the voice of medicine, is the "voice of the lifeworld" which refers "to the patient's contextually-grounded experiences of events and problems in her life" (Barry et al. 2001, pp. 487–489).

They cite the clinical encounter as a context where the voice of medicine can seek to colonise and silence the voice of the lifeworld to achieve the rational, purposeful outcomes of medicine (Barry et al. 2001, p. 488). The encounter is dominated by the clinician's objectives and the patient's lifeworld is effectively blocked from the conversation by focusing on symptoms, disease and treatment (Barry et al. 2001). In some instances, speaking predominately in the voice of medicine is effective, particularly when the patient is also seeking the same information. However, when the patient wants to include the context of the illness in their life in the conversation, such as the effect of treatment on their future ability to work or care for family, and the clinician speaks only in the voice of medicine, they can feel alienated and dehumanised (Barry et al. 2001).

Yet as Kneebone (2014) points out, clinicians are socialised to speak to each other with precision and clarity about the patient's anatomy, physiology

and pathology. Medical students craft their skills at editing and orating the patient's narrative of their illness. Called upon to demonstrate in medical rounds their ability to identify, diagnose and communicate the physical symptoms of the case history demands information is succinct, precise and detached from the patient (Kneebone 2014). Kneebone (2014, p. 1179) describes this technical voice as highly effective but limited because it has been "filleted of emotional content".

In an analysis of clinical interactions where physicians disclosed bad news, clinicians' deliveries were often factual and abstract which encouraged recipients' to reciprocate with "emotionally distanced" responses (Maynard 2003, p. 154). Shim, Russ, and Kaufman (2006, p. 17) describe this as a language that "forces objectivity and decisiveness," redirecting emotional responses toward rationality and control. Medical language, McNamara (2004) poses, can only speak of death in the context of "action, survival and effort" (Bauman quoted in McNamara 2004, p. 935). Consequently, disclosure of a life-limiting illness can quickly avert to focusing on treatment options rather than the possibility of dying.

Taylor (1988) identified in her research with seventeen breast cancer surgeons and 118 disclosure events, three phases of telling used by the majority of the surgeons. First, the conversation began with a "preamble" to "set the stage", leading to the "confrontation"; in this case the confirmation of the breast cancer diagnosis, followed by "diffusion" where to lessen the impact of the diagnosis, discussion shifted toward medical interventions (Taylor 1988, pp.116–117). Interestingly, although many of the surgeons considered they communicated an accurate prognosis to their patients, Taylor (1988, p. 116) categorised only ten percent of the events as this. In only fifteen percent of the events did the surgeons admit to being uncertain of the best way to treat the cancer and in the majority of events (45%), Taylor (1988, pp. 116–117) identified techniques of evasion, such as referring to general statistics where the correct technical response would indicate a poorer prognosis.

Friedrichsen and Milberg (2006) warn of the risks inherent in disclosure conversations where the emphasis is on engaging the patient in dialogue on treatment, particularly in the transition to palliative care. While they agree providing information is critical, along with emotional sensitivity and the willingness to talk about prognosis, the concern is patients can misunderstand the intent of the conversation and interpret their illness as treatable (Friedrichsen and Milberg 2006).

Lupton (2012) points out that clinicians too have their own lifeworld they bring to the clinical encounter that infuses with their voice of medicine. As such, Jutel (2009, p. 279) views the medical encounter as "a relational process with different parties confronting illness with different explanations, understandings, values and beliefs". In this way, Lupton (2012, p. 9) argues clinicians are not neutral observers in the disclosure process but are agents in re-orienting their patients to their new future through translating medical



knowledge to create a shared understanding of what this knowledge means for the patient. Barry et al. (2001, p. 491) suggest the reliance on the voice of medicine is necessary to some extent in any medical encounter and consider the voice of medicine is “not in itself inherently bad”. Though they conclude there is a need for doctors to be more open to discussing the concerns of the patient’s lifeworld, this too is contextualised to a medical system where time is limited, and doctors are trained to elicit patient information following a structured format of medical questions (Barry et al. 2001).

In contrast, Frank (2004, p. 78) warns against the medical voice that speaks in a monologue about the person with disease rather than to the person who is before them. However, the literature points to how, through the language of medicine, spoken with social and cultural authority, patients and their families come to understand directly and intuitively not only what is expected of them, but what to feel (Timmermans 2005; Shim, Russ, and Kaufman 2006).

## Medical Time

The impact of the economic value accorded to medical professionals’ time on the disclosure of a terminal diagnosis cannot be underestimated. Physicians’ time is a high-value commodity that must be managed accordingly in the context of increasing demand for health-care and diminishing budgets (Frankenburg 1992). The imposition of structured medical care means disclosure conversations are contained to the time available in clinics or patient rounds.

In contrast to the physicians’ immersion in medical culture, for many patients how time is structured and prioritised to the tasks of the medical project unfolding can be bewildering and antithetical to their experience of being unwell. Laranjeira, Leão, and Leal (2014, p. 14) highlight the contradiction between the patient’s need for a more flexible rhythm when “clock time” and routine is disrupted by illness and a health care system with an emphasis on “hectic turnover or throughput of patients and an ever increasing pressure to discharge early”. Similarly, Frank (2004, p. 139) highlights how “being ill slows our pace” and yet rather than attune to the patient’s needs, “institutions expect everyone to speed up”.

Shim, Russ, and Kaufman (2006, p. 8) define the role of time in the medical system as “the marker for things health professionals think should happen and for things that must get done, and it weighs heavily on everyone”. Time is of the essence in the battle to hold back death, leading to what Chapple (2010, p. 89) describes as a “ritual of intensification” clinicians use to “redouble” their efforts, justifying the use of corrective interventions in the moral and ethical fight against death. Notably, Mosenthal, Lee, and Huffman (2002, p. 76) report in their research on surgical culture where death can be seen as failure, aggressive curative intent dominates the goals of care are “often

focused on procedural endpoints, morbidities, and mortalities, rather than patient-oriented goals or quality of life”.

Even in the transition to palliative care, decisions to continue treatment are presented not just as a way to alleviate symptoms but also to “buy time” and hold off death for as long as possible (Chapple 2010, p. 70). However, the irony of “hospices hope work” as Chapple (2010, pp. 100–101) points out, is that patients must give up the expectation of “more time or more therapy” in the acceptance of dying and hope of a good death. This peaceful, good death informed by the death revival movement can only come when “hope for recovery is to be officially abandoned” (Chapple 2010, p. 187). She asserts that clinicians express satisfaction when dying is on time and without surprises so that family and loved ones are in attendance and physical symptoms are seemingly controlled (Chapple 2010).

### **Communication Skills**

Studies indicate the way disclosure of a terminal diagnosis is communicated and managed can positively influence how well the patient makes the adjustment from treatment to palliation (Schofield et al. 2006). As a response to a mostly negative evaluation of medical practitioners’ communication skills, there are a range of models outlined in the literature developed for physicians to use when disclosing negative or bad news (Meier, Back, and Morrison 2001; Baile et al. 2002; Boyle et al. 2004; Sweeny and Shepperd 2007; Legg and Sweeny 2013). These are designed to fill the gaps that have not been addressed in medical school training and professional development. However, the critique of clinicians’ performance is ongoing, which brings to question both the validity of focusing on communication skills and the efficacy of these models to address it (Hagerty et al. 2005).

This focus on communication techniques, styles and models for “breaking bad news” is so frequently discussed that in some medical journals it is simply referred to as the acronym, “BBN” (Barnett 2002; Shaw, Dunn, and Heinrich 2012; Shaw, Brown, and Dunn 2013). Many of these techniques are designed to support and guide clinicians to disclose the diagnosis to their patients with emotional acuity and sensitivity. Equally, as with any communication management technique, they can be strategically deployed, not always intentionally, to modify how disclosure is communicated but not necessarily change the intent of what is being communicated. Good et al. (1994, p. 858) identified what they termed “narratives of immediacy” used by oncologists to explain and justify the focus on immediate actions and interventions (p. 858). They observed oncologists “deflecting” discussions of prognosis by “drawing patients back” to discussions on treatment where “endings are rarely made explicit and progression is measured in calibrated bits, even though disclosure is considered to be the norm, a patient’s right in American medicine, and frankness is valued” (Good et al. 1994, p. 858).

Kasket (2006a) reflects on the research interviews she conducted with physicians and noted how the process of deflection was frequently used with her. She found it difficult to move the conversation away from communication skills issues in order to get the physicians to talk more about the emotional processes of telling patients and families a poor prognosis. She describes this as though the physicians had “so thoroughly and strongly internalized feelings about not feeling or expressing personal emotion about patients that they found it difficult to comprehend that I was asking about this aspect of experience” (Kasket 2006a, p. 394). This resonated with my own research experiences where the theme of the research project was most often interpreted by the physicians I interviewed as a focus on communication styles and how best to disclose a terminal diagnosis or prognosis.

## **A Single Moment of Telling or a Process Unfolding?**

Diagnosis is integral to the system of medicine providing legitimacy and authority to present an ordered account of the disordered set of symptoms which bring patients to the clinical encounter (Jutel 2009, p. 278). In this way, diagnosis frames and focuses the clinician’s view of their patient. In the clinicians’ narratives from this research, diagnosis is the starting point; where the possibility of disclosing a life-limiting illness begins, and sometimes ends. Diagnosis is inextricably linked to disclosure; “the foundation from which sense-making and experiences are crafted” for the patient and clinician alike (Jutel and Nettleton 2011, p. 794).

In the process of diagnosis, both patient and clinician must navigate the structure of medical care, often fragmented by medical specialisation and associated professional boundaries (Jutel and Nettleton 2011). For the patient the often multiple diagnostic events leading to the disclosure of a terminal diagnosis or prognosis can allow time for contemplation of treatment failure. However, this is in stark contrast to the clinician for whom the testing, diagnosis, consideration of treatment options and management of palliative care might evoke a sense of routine, with less acute boundaries (McManus 2012). These diagnostic processes and treatment regimens can provide a level of predictability and back-stage preparation for the clinicians’ disclosure performances (Goffman 1959). However, I argue that over the course of the illness trajectory the physician is required to do more than disclose the outcome of the diagnosis. Rather, there is a careful negotiation with the patient to seek their ongoing trust and commitment to the pathway of medical care and salvation from suffering (Good 1994).

### The Centrality of Diagnosis to the Physicians' Experiences of Disclosure

Diagnosis, is described by Brown (1995, p. 39) as “the language of medicine” and by Jutel (2009, p. 288) as “the fulcrum of the medical narrative” situated at the intersection of the patient’s lived experience of an illness and the clinician’s medicalised version of their story.

Learning to identify and present this medical narrative, is according to Kleinman (1988) based on the medical student developing a scepticism for the patient’s story. The patient, Frank (1995) claims, is expected to surrender their narrative to this process when seeking care so the true facts of the illness can be determined. In return, diagnosis provides access to what Parsons (1951) described as the sick role for the patient; legitimising permission to be unwell and authorising an exemption from the responsibilities of day-to-day life.

In a study of medical residents conducting admissions interviews, Davenport (2011, p. 873) analysed their “diagnostic storytelling” to identify how they determine the answer to the most fundamental questions of “what’s going on here?” Working in a short period of time from first encountering the patient to presenting their case history to other physicians, residents habitually employed “narrative templates” to determine how to organise what facts are relevant based on their medical knowledge of disease, treatment, outcomes and what they have learned of the patient from their records (Davenport 2011, p. 874). Without applying some form of “organizing filters” Davenport (2011, p. 875) reasons physicians would be overwhelmed by the amount of information in patient’s case files and in their narrative.

Leder (1990, p. 18) draws on hermeneutics and a narrative analogy, describing diagnosis as an interpretative process whereby the patient presents with symptoms of bodily events that the physician reads as a text in order to take over the authorship and transform the story, so that they can “wrest the story from its malignant author and write a happier conclusion”. Interpretation is aided for the physician from reading secondary texts. He identifies these as the narrative text, or case history, the physical examination and the instrumental text such as diagnostic tests and scans (Leder 1990, p. 11). Reading these texts commences from the earliest encounter with the patient, informing what information the physician chooses to seek and prioritise from the patient’s narrative and the instrumental texts (Leder 1990, pp. 16–17).

However, Leder argues that medicines’ claims to “purified objectivity” have led to a “flight from interpretation” with physicians seeking to “free themselves from the patient’s restricted perspective and the subjectivity of their own perceptions” toward a much greater reliance on instrumental texts (Leder 1990, pp. 20–21). Nevertheless, these seemingly objective texts are also subject to interpretation, and therefore misinterpretation. For example, Moskowitz (2010, p. 127) cites a retrospective study of mammography re-

ports that showed significant discrepancies in the readings of radiologists and their treatment recommendations. Nevertheless, the instrumental text is often referred to in disclosure conversations as scans and x-rays are presented to patients and their families as proof and at times independently from the physician's diagnosis (Rosenberg 2002). The attention on scans and test results can also act to deflect attention away from the emotional responses to a poor prognosis or diagnosis toward the management of the physical disease.

In the literature on the sociological analysis of diagnosis, the identification, classification and naming of disease is considered in the context of its centrality both to the system of medicine and in creating social order (Rosenberg 2002; Jutel 2009; Brown, Lyson, and Jenkins 2011; Jutel and Nettleton 2011; McGann and Hutson 2011). Diagnosis provides a framework for organising illness, determining treatment options, predicting responses to treatment and explaining disease (Rosenberg 2002; Jutel 2009; Brown, Lyson, and Jenkins 2011; Jutel and Nettleton 2011; McGann and Hutson 2011). Rosenberg (2002, p. 256) concurs stating that even if the expectation of a diagnosis cannot be met in the clinical encounter, the process of diagnosis is still "socially efficacious" because "anxiety and mystery can be ordered, if not precisely allayed".

How disease is categorised and diagnosed is contextualised more broadly by Brown et al (2011) who consider the interplay of economic, political and cultural structures on diagnosis. They point to diagnosis as a social process beyond the individual to disease within the wider population. Multiple actors such researchers, government agencies, commercial entities, social movements are seen as contributing to an understanding of disease.

Jutel (2009, p. 278) positions diagnosis as a "powerful social tool" reinforcing the authority of medicine and its practitioners in the identification and explanation of illness and disease. Even in the context of greater patient autonomy and engagement in medical care, it is clinicians who can use their discretion to decide on their patient's behalf if further investigation is warranted (Jutel 2009). This is viewed as an element of the doctor-patient relationship that has survived from the paternalism of days past where the clinician "remains the key arbiter and thereby still holds significant jurisdictional authority" (Jutel and Nettleton 2011, p. 796). Furthermore, it is through the process of diagnosis that insight into the organisation of medicine and the "interplay between medical care providers and professional territories" is revealed (Jutel and Nettleton 2011, p. 799).

Rosenberg (2002, p. 256) alerts the reader to the assumption of diagnosis as a "discrete act taking place at a particular moment in time" even though it is frequently a "collective, cumulative, and contingent process". In research by Salander (2002) cancer patients' narratives of the disclosure of their diagnosis were analysed. It was found patients generally talked about a longer process, from their first contact with clinical staff and ending with conclusion of treatment, therefore arguing the focus is never on a single moment.

Schaepe (2011) also supports the concept of disclosure as a process but

then goes on to describe three circumstances patients recall being told their diagnosis, suggesting there is a moment at some point in the process patients or their families remember as significant. In the first of these situations patients were in an emergency department and did not recall hearing the diagnosis although their caregivers did “feel the full force almost immediately” (Schaepe 2011, p. 916). This contrasted with the primary care setting where patients were told during a visit to the doctor and then faced having to tell loved ones after, in what was described as a “two-stage trauma” (Schaepe 2011, p. 916). In the final setting patients were diagnosed with a secondary cancer that had developed or recurred a year or so after the first diagnosis. This too, seemed to be both a process of diagnosis that culminated in a moment of disclosure, the impact of which was recalled by some patients using metaphors such as “a blow” (Schaepe 2011, p. 916). The reference to metaphors of violence with the news of disclosure is also referred to in Gordon and Daugherty (2003) *Hitting you over the head: oncologists’ disclosure of prognosis to advanced cancer patients*. The use of such metaphors seems to indicate an immediate reaction to a shock that is felt as an assault (Schaepe 2011).

Maynard (2003, p. 12) reports that for the patient, disclosure can be experienced as a “graphic moment”, often recollected because it is subject to frequent rehearsal with the telling and retelling to family, friends, employers in the process of sense-making and reorganisation of their lifeworld that follows. It is perhaps Willig (2011, p. 898) who offers an intermediary and more workable position suggesting the “cancer journey” is a trajectory punctuated by “crisis points” (Coward, quoted in Willig 2011, p. 898).

### The Ongoing Negotiation of Trust

Following disclosure, Page and Komaromy (2005, p. 306) identified how patients and their loved ones lives are recast as “the time before, and the time after” the diagnosis. The future must be re-imagined; the planning of what comes next and goal setting projected into a medical future (Page and Komaromy 2005).

Multiple consultations may be required in the process of determining a final or resolute diagnosis, a process eloquently described by Jespersen and Jensen (2012, p. 348) where each consultation “works as a form of folding machine: it connects points that were previously distant in time and space”. Not all consultations follow a predictable path and the time in between consultations are also a significant but different part of the process for the patient and the clinician (Jespersen and Jensen 2012, p. 348). In a study by McQueen (2009) of patients waiting for a possible cancer diagnosis indicated many experience acute distress and anxiety. Recipients reported experiencing a distorted sense of time waiting for, and receiving bad news in the encounter (McQueen 2009). Maynard (2003, p. 12) describes the distortion of time such that “one’s inner sense of duration can expand or contract relative to clock time... it may be

agonizingly long or startlingly short as breakdown of the taken-for-granted occurs”.

This positions the physician as continually needing to renegotiate trust and confidence in their medical expertise while possibly working with little certainty of what the diagnosis may be, in effect, seeking the patient’s continued trust in the likelihood of further uncertain testing and treatment options (Schaepe 2011). Schaepe (2011, p. 912) draws on research indicating that “trust is an outcome of situational predictability”. For cancer patients and their families/loved ones the need for stability and to be able to trust the system and physicians were competent was high (Schaepe 2011). Hence clinical encounters very early into the diagnosis process served as defining “trust-building or distrust building experiences” where the staff and the hospital were closely scrutinised (Schaepe 2011, p. 918). How effective these encounters were at building trust could determine how bad news and subsequent medical interventions would be experienced by the patient (Schaepe 2011, p. 918).

For the physician, disclosure of test results and further prognosis can be complicated when there is no clear indication ongoing testing and treatment will produce the anticipated outcomes. Williams (2005, p. 137) notes that ironically and paradoxically, the advances of medicine that sought to address medical uncertainties, have indeed generated greater medical uncertainties that impose significant strain on the clinician and their interactions with their patients. Bradby (2009) also talks of how symptoms can infer a multitude of causes, many of which can now be tested for, at a refined cellular level previously unavailable. This may produce a clear diagnosis for some illnesses such as diabetes, but for other cases, it can result in an ambiguous, sometimes even contradictory diagnosis (Bradby 2009). When medical treatment fails, disappointment and uncertainty emerges, for example when young lives are lost or illness is debilitating and ongoing and there are few explanations to offer meaning in these situations (Lupton 2012, p. 8). Yet, as Lupton (2012) suggests dependence on medicine in times of ill-health continues.

### **Telling as a Rite of Passage**

The influence of the medical practitioner on the disclosure process and the dying role is deemed by some to extend beyond simply communicating a diagnosis or prognosis. Disclosing bad news has also been considered as a ritual, representing the threshold to the liminality or transition between exiting one social world; health, and entering another; illness (Maynard 2003, p. 11). In this sense, diagnosis and disclosure are rites of passage to the transition from health to illness that ends when the patient re-enters with a new status of cured or dying (Little et al. 1998; Blows et al. 2012).

Boland (2013) describes liminality as characterised by disorder and a time when the social order, or what we thought we knew, is questioned. In re-

sponse, people withdraw from what they knew as the normal modes of their lives. Correspondingly, during this liminal time of the ritual process Boland (2013) is of the view there are traditionally more freedoms with fewer limits on behaviour. To ensure behaviour is managed so the ritual is completed, Boland (2013, p. 230) outlines the role of “masters of ceremonies” who are often in attendance to guide the participants through the transition. In this way, clinicians can be considered as masters of ceremonies guiding patients through the upheaval of illness, ensuring they reassemble their experiences in culturally and socially preferred ways (Boland 2013).

The risk is when patients refuse to enter the liminal transition or exit unexpectedly; the ritual is not completed, leaving the clinician and patient bereft and separated from the culturally sanctioned identities (Blows et al. 2012). With increasing survival rates for many cancers, Blows et al. (2012) see patients and clinicians trapped in an extended liminality where the threat of recurrence prevents a clean exit and holds both in confused state of health and illness care in perpetuity.

### Death-brokering

Timmermans (2005, pp. 993–994) draws on the analogy of insurance brokers, arguing medical experts are brokering “the existentially frightening and ambiguous aspects of death and dying” on our behalf. “Death-brokering” according to Timmermans, expands the telling of death to the negotiation of cultural expectations of the acceptable line between “curing or letting go, achieving a ‘good’ death and avoiding ‘bad’ deaths, attributing legitimate responsibility for the death, and determining relevant lifestyle and therapeutic changes to keep on living” (Timmermans 2005, p. 994).

Charged with managing and explaining death, Timmermans (2005) reasons the authority of medical professionals is unquestioned and reinforced through an ever-increasing dependency on medical experts’ involvement to offer solutions to an ever-increasingly medicalised process of dying.

Guiding a patient toward the trajectory they have “brokered” requires a skilful presentation of themselves as competent and caring medical professionals who can be trusted to deliver the agreed outcome (Timmermans 2005, p. 995). Page and Komaromy (2005, p. 295) consider medical professionals’ behaviours with patients, families and staff in light of Goffman’s (1959) metaphorical presentation of self as a dramatic performance of impression management.

The patient’s perception of the clinician and their acceptance of future management of their life-limiting illness are based on how well the clinician can negotiate their trust (Schaepe 2011). This suggests in part, negotiating the patient’s trust draws on the professional status of medicine in society and the culturally and socially determined expectations of how medicine will manage the care of dying patients (Page and Komaromy 2005). Clinicians’ enactment



of “scripts” convey impressions of professionalism, particularly when there is consistency with appearance, setting and manner (Goffman 1959, pp. 21–22). Drawing on Goffman’s (1959) theories of impression management brings into question how longer and repeated processes of diagnosis or the “temporal length of the performance,” affect the physician’s experience of disclosure. In addition the clinician is often performing in front of multiple audiences such as the patient, their loved ones, and even multidisciplinary care teams (pp. 27,215) .

### **Doctor–Patient Relationship**

The relationship between doctors and their patients has shifted and changed as patient advocacy groups and the increasing rise of active health consumer awareness has heightened social awareness of the traditional asymmetrical nature of the doctor-patient relationship (Lupton 1996; Lupton 1997; Williams 2005; Thompson 2007).

Consumerism in health care assumes the patient is willing and able to evaluate, select and voice complaints about health services; challenge medical decisions and “resist paternalism or medical dominance” (Lupton 1997, p. 373). Access to health information and support from self-help and voluntary groups, alongside an abundance of health information available on the internet have had a significant impact on the doctor-patient relationship (Thompson 2007). The shift to a focus on chronic health conditions is cited by Thompson (2007) as an example of the wider influences on health care. The knowledge and contribution people with chronic conditions make to managing their illnesses has led to their recognition as expert patients in health policy (Thompson 2007). In addition there has been a shift towards “incorporating patients’ perceptions, values and preferences into a more subjective medicine, moving health care goals towards quality of life and patients’ perceptions of health” (Thompson 2007, p. 1298).

Consequently expectations of the role of the physician have also increased as they must now navigate the dynamic shifts in the patient’s role with a profound emotional acuity and technical accuracy in the context of complex medical uncertainties. Lupton (1997, p. 380) in her critique of health consumerism discourse develops the claim that some patients may seek a relationship of dependence on a paternalistic doctor, “even as this confounds expectations around ‘consumerism’”. Furthermore, she holds it is possible to consider the health consumerist movement evokes a “rationalist anti-authoritarianism against an ‘other’ (in this case members of the medical profession) defined as controlling” (Lupton 1996, p. 169). Yet when patients are seriously ill and frightened dependency on doctors can increase and rather than see the doctor as an authoritarian ‘other’ they are a welcomed and reassuring presence (Lupton 1996, p. 169). Lupton (1996, p. 165) positions the exchange of care between patient and clinician in the medical encounter as a commercial and

professional transaction, based on duty and payment of fees with an expectation the patient will respond with “gratitude, docility and compliance”.

In recent shifts away from the more traditional paternalist relationship, patient-centred medicine is upheld in public health policy discourses of concordance; a concept developed from an investigation into the failure of patients to comply with treatment regimens (Bissell, May, and Noyce 2004; Stevenson 2004). According to Stevenson (2004) concordance is premised on the patient and doctor working as equal partners in the negotiation of treatment plans and a greater understanding of the implications of that treatment on the patient and their lifestyle. Concordance also assumes a respect for differences discussed openly and rationally in the context of an equal partnership (Stevenson 2004). Yet, Bissell, May, and Noyce (2004, p. 860) critique the concept, arguing concordance retains a focus on changing the patient’s attitudes, not the clinicians. In this way, they see concordance as another model of patient-doctor relations that risks being used to impose medical views on how patients should behave (Bissell, May, and Noyce 2004).

Conrad (1985, p. 25) stresses that not all people share their doctor’s view as they “feel and act on symptoms in many non-medical ways” so that what seems to be irrational noncompliance “may be a well-thought-out plan to avoid medical and social ‘side-effects’ which might impair personal and work life” (Brown 1995, p. 45). Field (1996) too, considers even the dying role may be influenced by expectations of medical practitioners. Ironically it is the hospice model, premised on supporting the patient to die the way they want, he cites as an example of this influence. Underpinned by the happy, positive death discourse, Field (1996) points out it would be very difficult for a patient to resist and die unhappily with rage and anger in a hospice.

Patients come to the clinical encounter with their own lifeworld understandings, concepts and meanings, hopes and plans. These are shaped by past experiences with medical professionals, other people’s experiences and information from social media as well as patients’, class, gender, age, ethnic or racial groups (Lupton 2012). Ultimately, however concordance could mean negotiations may fail and in the end the patient and doctor agree to differ.

The question this raises for the disclosure of a terminal diagnosis or prognosis is what it means for clinicians when patients resist, refusing to accept the diagnosis or choose to walk away from the treatment and care clinicians can provide.

## Failure and Demoralisation

The pressure on physicians to perform in socially, culturally and professionally prescribed ways when caring for dying patients can lead to a demoralisation of medicine and medical practitioners. When treatment fails or patients choose not to accept the treatment offered, physicians can experience feelings of frus-

tration and failure. Little support is available for clinicians to express these feelings with powerful professional norms influencing physicians' ability to acknowledge emotional pain. In addition, physicians must negotiate the care of their dying patients within tightly managed allocations of their time by the medical organisations for whom they work. As such they are challenged with finding ways to manage the relationship with their dying patients so they do not feel abandoned and alone. Yet, often physicians are siloed into specialities that mean they rarely have the opportunity to care for their dying patients to the very end or say goodbye. This brings to question the impact of the cumulative exposure to at times tragic and difficult patient deaths on physicians and what, if anything, can be done to change this.

### Failed Performances

Nuland (1994) describes the need for control as a factor in the personalities of many physicians he has worked alongside. He argues "when control is lost, he who requires it is also a bit lost and so deals badly with the consequences of his impotence" (Nuland 1994, p. 258). Failed performances in telling, brokering and guiding in the disclosure and subsequent journey to the ideal cure or peaceful death sometimes provoke anger, embarrassment or humiliation for clinicians and raise suspicions of medical mismanagement if patients or families feel wronged (Goffman 1959; Timmermans 2005).

Charon (2001, p. 1898) in her work on narrative medicine, positions medical practice within a series of relationships, "between the physician and the patient, the physician and himself or herself, the physician and colleagues, and physicians and society". She, like Frank (2004), considers how connections between these relationships can be improved through listening to patients' narratives that "demand the courage and generosity to tolerate and to bear witness to unfair losses and random tragedies" (Charon 2001, p. 1899). However, others have critiqued her approach, warning of the additional and possibly unrealistic expectations of "superhuman empathy" this establishes for patients and doctors alike (O'Mahony 2013, p. 614).

Macnaughton (2011, p. 1941) from the Centre for Medical Humanities in Durham, cautions against thinking feelings such as empathy can be taught. She stresses the suggestion it is actually possible to feel what another person is feeling is both dangerous and unrealistic because "we cannot gain direct access to what is going on in our patient's head". She concludes: "a doctor who responds to a patient's distress with 'I understand how you feel' is likely to be both resented by the patient and self-deceiving" (Macnaughton 2011, p. 1941).

The dynamics of emotions at play are unpredictable but likely to be expressed by the patient with an intensity few others experience in their daily work (Kasket 2006b). It is also likely that those emotions are sometimes experienced as acutely by the physician. Meier, Back, and Morrison (2001)

documented physicians' feelings of inadequacy, frustration and failure as common responses to this situation. Yet, Grönlund, Dahlqvist, and Söderberg (2011) identify expectations of physicians to operate largely independently and alone. This creates a culture where they are often unwilling or unable to have time with their equally busy colleagues to discuss the less medical aspects of what their work entails (Grönlund, Dahlqvist, and Söderberg 2011).

Charon (2001, p. 1900) reasons because doctors "educate and police one another" they also take on responsibility for their fellow practitioners "competence and conscience.". Wallace (2010, pp. 7–8), in her research into mental health and stigma in the medical profession talks of "the conspiracy of silence" where physicians are reluctant to recognise or talk openly about any psychological problems that might be due to their stressful working conditions. Reinforcing normative behaviour and stigmatising deviance from that norm, sets up the potential for substantial risks to the physician who dares to disclose their own emotional pain lest it be considered irrational and an impediment to their technical competence (Wallace 2010). Frank (2004) shares this view articulating a particular aloneness that is in stark contrast to the pretence of collegiality and membership in the medical profession.

### **Demoralisation and Burn-Out**

It is not surprising that a theme in the literature is the burn-out of medical practitioners in the face of the resilience they are expected to develop from early on in their career (Ramirez et al. 1995; Meier, Back, and Morrison 2001; Kurer et al. 2007; Jackson et al. 2008; Guest et al. 2011; Roth et al. 2011; Jasperse, Herst, and Dungey 2014; Shanafelt et al. 2014; Poulsen et al. 2015). Where there is research on their personal experiences of emotional and ethical difficulties, it is problematised and to some extent individualised indicating that dominant discourses of rationality and stoicism in medical professionalism may be threatened by narratives of mental illness (Cochrane et al. 1991; Wallace 2010). An inability to sustain the psychological and physical endurance expected, risks disrupting not only the professional norms but according to Bradby (2009) also risks disrupting the social order of medicine that expects a social good model of medicine to prevail.

Doctors adopting what is sometimes referred to as an "emotional suit of armor" in the literature, to hide their real feelings and present the emotions expected are at risk of losing touch with what they really feel (Aronson 1966 quoted in Kasket 2006, p. 139). As a result Frank (2004, p. 86) asserts doctors and patients become isolated and estranged, no longer able to respond with generosity toward each other, resulting in what he describes as a "demoralization" of medicine.

It is the system of institutionalised medicine that Mildred Baxter holds accountable for creating a sense of "alienation" from doctors and their patients (quoted in Jutel & Nettleton 2011, p. 797). While Frank (2004, p. 27) too

acknowledges there are many reasons why the practice of medicine is impacted by how medicine is organised he maintains these reasons can become “multiple alibis” to “truncate care”. Rather, he returns the focus to the individual, arguing “in the interpersonal moment of practicing medicine, anyone can act differently” (Frank 2004, p. 28).

Frank (2004) attributes the pursuit of curing illness and disease as a way of buffering and distancing humanity from the incurable. Instead death is rarely talked about and yet, as Callahan (1993, p. 129) states, “death is a universal human experience, and it derives its meaning as much from this universality as from the different circumstances of individual lives and deaths”.

### Remoralising Medicine

When the focus on cure is no longer plausible, patients judge the physician on how well they have conveyed a sense of comfort that might mitigate any perception of abandonment by the medical system (Mast, Kindlimann, and Langewitz 2005). Yet Back et al. (2005) found discrepancies between what clinicians stated they did to avoid this and patients and families experiences. Poignantly, Back et al. (2005) write of how clinicians rarely say goodbye to their patient and families when it is unlikely they will attend any further clinics. They suggest not saying goodbye risks leaving patients and their families perplexed and although this may not be appropriate for all patients, acknowledging the end of the therapeutic relationship can be “deeply meaningful” and “a way of embodying the scope and power of one’s limits as a physician” (Back et al. 2005, p. 684).

Gawande (2014, p. 293) in his book *Being mortal: medicine and what matters in the end* critiques the medicalisation of death and dying and as the title suggests reminds us that “endings matter”. He advocates confronting the reality of dying with patients rather than pretending it can be beaten. Gawande (2014, p. 306) argues this means there has to be an understanding that “there are times where the cost of pushing exceeds its value” in order for the medical establishment to be able to offer the compassion that allows for more humane ways to die.

Remoralising medicine, according to Frank requires finding ways to combat isolation and connect with patients and colleagues to “restore generosity” (Frank 2004, p. 137). This shift in approach recognises and seeks to include the expression of emotional pain yet as Frank (2004) points out this is rarely afforded to those giving the care. Kasket (2006a, p. 395) concludes in her paper with two stories involving patients with horrific injuries and tragic death told by physicians during her research. She is struck by the “carnage” and confrontation with death physicians are often exposed to in their work that few outside the profession would ever witness (Kasket 2006a, p. 395). Yet the high potential for post-traumatic stress as a result is “scarcely apprehended” (Kasket 2006a, p. 395). She too ponders how things could be different if expec-

tations of doctors by others and themselves were questioned more frequently and the stigma of physicians accessing psychological support was diminished (Kasket 2006a)

## Conclusion

The myriad of often conflicting views in the literature of how clinicians should respond to patients, colleagues, and their own needs positions the process of disclosure of a terminal diagnosis or prognosis within an array of critique and expectations. In the literature, disclosure practices and processes are influenced and shaped by the organisation of medicine and medical socialisation, cultural and social expectations of medicine and the management of death and dying and organisation of medicine and powerful narratives of ideal deaths. Within this are theories and commentaries on the motivations of physicians in the disclosure process and the degree to which they determine when and how much information on a terminal diagnosis or poor prognosis is communicated to a patient and their loved ones. Situated within a complex realm of narratives in the literature that both glorify and demonise the medical profession, the physician is asked to negotiate the pre-conceptions and expectations of the patient to deliver a message that confirms their death is imminent. The clinical encounter is viewed by Charon (2001, p. 1900) as the site of a complex interplay of individual needs and socially constructed responses where “granting tonic authority to its physicians while regarding them with chronic suspicion, the public commands physicians to understand and treat disease while doing no harm”. How this resonates with the experiences of clinicians in this research engaged in the practice of disclosure with patients is explored in the narrative analysis that follows.

## Chapter 5

# Biographies

### Introduction

In the five biographies that follow I have written of the characteristics of each clinician emerging from their narratives based on the interviews conducted. Experiences they shared often served to illustrate their values and beliefs which were apparent in the way they practice medicine. Focusing on the disclosure of a life-limiting illness to their patients they revealed a broader contextual landscape from which to understand how the clinicians' experiences were often markedly different.

Each clinician came to medical school with their "lifeworld" experiences and the completion of at least seven years of medical education was followed by further specialisation. Consequently, in their own unique ways they have learned to speak with the "voice of medicine" (Barry et al. 2001, pp. 487–488). However, socialisation to this culture has been experienced differently and integrated to varying degrees with their own lifeworld values. How each clinician experiences the disclosure of a life-limiting illness to their patients, it could be argued, is an indication of how successfully they have been socialised to the culture of the medical profession.

Some of the clinicians recalled early career experiences that speak of being witness to situations where patients were ignored or abandoned by senior clinicians. The complex and nuanced process of disclosing a life-limiting illness to their patient occurs within the clinical encounter that is embedded within and shaped by, the cultural contexts of medicine. It is a culture that has influenced and informed how each of the clinicians has learned to 'tell'. They all recalled being taught some form of communication skills in medical school. For Dr Z, the oldest of the clinicians interviewed, there was little emphasis on this whereas Dr X, the most recently trained, talked of specific modules on "breaking bad news" in medical school that was a feature of her specialisation in general practice.

There is a sense that for some, despite the vast amount of research that

informs models and medical school curricula of teaching communication skills, including “breaking bad news”, experience on the job has continued to be the primary and most valued source of learning. Their narratives of experiences as medical students infer for some a resistance to the normative behaviour of other medical practitioners. The process of ‘cherry-picking’ is recalled as a way of selecting the good from the not so good, of how to behave with dying patients. Some clinicians recount their reactions to significant formative situations. They are experiences that have informed how they wanted to be, not only because the behaviour they witnessed was antithetical to their values of how people as patients should be cared for, but importantly, because of how they, at the time chose to respond to the situation that unfolded.

How they negotiate and attempt to resolve the conflict in their values experienced in these encounters conveys how they practice medicine today as senior clinicians. Embedded within this dominant culture, narratives of their learning, particularly where the collision of lifeworld and medicine occur, have significance in their experiences with dying patients.

## Dr X

Dr X had a period of twelve years working when she left high school, followed by nursing training then medical school. Now qualified for thirteen years, Dr X works in two medical roles. Dr X drew on formative experiences from nursing and medical school; a primary feature of Dr X’s narrative was the power dynamic inherent in the way medicine is structured. As a student nurse asked to sit with a man who was near death, she felt unprepared and unsupported. Unsure what to say to this man estranged from family and dying alone, Dr X faced a personal and professional dilemma. New to both Christianity and nursing, Dr X sought to comfort her patient. She said to the unconscious man, “*Do you know god loves you?*” At once his breathing eased, he opened his eyes, looked at her, and with a sense of peace prevailing, died.

*“But yeah I think that was one of the most powerful things that first taught me about how important it is about being ok, about trusting your unique self to do what you feel you need to do and follow through on that...”*

It was a powerful and significant experience for Dr X and symbolic of the tension, uncertainty and discomfort she experiences when her values jar with the often contradictory discourses of medical professionalism. On another occasion as a junior doctor in the emergency department, a woman in her forties who was having difficulty balancing and was “*banging into things in the supermarket*” was admitted. The woman was sent for a head scan and the results reveal she had brain metastases from lung cancer. The disclosure of the diagnosis was handed to Dr X:



*“...it felt wrong because I think that I felt like other people had opted out. I tried to do it in the best way that I could but it was like, yeah, it was like she seemed to have no warning that this could be coming and then anybody who would have more experience in delivering this information than me was not going to be part of that, and yeah, it was left to me to do it.”*

Dr X's early experiences influenced how she strives to communicate bad news in her own practice, “so I think when I've had the opportunity to do it, I've wanted to do it well but at the same time it's not necessarily a comfortable thing to do with people.” Despite feeling *“there's a lot of uncertainty attached to it,”* Dr X accommodates this in an acute awareness of her inner self; an intuition she draws on to guide her actions and inform her sense of right and wrong. Her courage to trust and act from her own values is sometimes counter to the medical model:

*“The medical model, it's just very much about symptoms, have you got this, have you got that, and not really about the how and why and the curiosity to find out the whole picture about someone. I think if you do that you'll find that what people want to know is not what you think they want to know. I think you have to let yourself be vulnerable to not knowing anything sometimes.”*

Dr X evaluates her choices of how she communicates and cares for her patients, compared with her colleagues. It is a system she is at times outside of, and othered by:

*“In your work as a general practitioner too, you really work on your own so you're not really sure how other people do things so you never quite know where you sit in the continuum of all those kind of things.”*

Dr X references experiencing how tenuous life is for her patients, where she is acutely aware bad news is constituted in many forms particularly for vulnerable elderly patients:

*“...I see all these things as bad news, delivering bad news, like it's just not ‘oh well you've got a terminal illness.’ It's like, ‘you can't drive anymore’ and to me it feels like bad news because I feel sometimes really powerless in how to help people because everything seems to become much more difficult when people get old.”*

If Dr X feels powerless to help this does not prevent her from trying hard to navigate a healthcare system that *“could be a lot more smooth running in delivering things for people.”* Guiding Dr X in her practice is a determination

to never let her patients feel there is nothing more that can be done for them, least they feel abandoned; *“I have the sense that instilling hope in people is a really core thing of my values.”* Her effervescent style, evident in the passion with which she shared her experiences, saw her frequent laughter spilled into tears and back to joy. She was very comfortable in her ‘uncomfortable’ experiences. She consciously accommodated the discomfort inherent in her assessment of her own and other’s actions. That this might wake her in the night is not hidden in her narrative, but brought forth as part of how she dynamically made sense of her world:

*“I find I wake up in the night quite frequently, that’s the time... I’m not quite sure how you necessarily do anything about that because they haven’t been conscious in the day time but clearly there’s subconscious processes going on sorting, you know, trying to sort things out.”*

Throughout her narrative, Dr X reflected on how medicine is organised, practiced and taught, often questioning how this is so, and how it could be better. She meets her patients as people, seeking to consciously care for them as autonomous and knowledgeable participants in their journey with her:

*“I think in terms of my expectations of myself and trying to feel conscious of being able to, not being all things to all people, because clearly you can’t do that and I know that, but feeling like you’ve had, or hoping that the other person has had an experience which is beneficial and uplifting for them, because that’s important to me and I don’t know if I get it right or I don’t, but certainly that is my intention. And I don’t know whether being really conscious makes your life harder or not. Sometimes it feels like it does (laughs).”*

Harder or not, Dr X was comfortable with the ambiguity and uncertainty her self-reflective practice of medicine facilitated in a way that was uniquely her own.

## Dr K

Dr K’s pathway to palliative medicine unfolded after a number of years in general practice offshore. Many of his patients were elderly so he was diagnosing and managing a lot of terminal illnesses. Dr K was doing continuing medical education to enhance his skills in this area, particularly because there were no hospice services available. Taking on an additional role supporting the development of a hospice ward in a nearby hospital, Dr K realised how much he enjoyed this work, *“it’s quite a rewarding area to be in; also, when you’re in a palliative care team, you’re never carrying any of this stuff by yourself.”*

Relocating to New Zealand he undertook specialist training in palliative medicine and is now medical director of an urban hospice. Palliative medicine is a place where Dr K feels he can make a huge difference by managing patients' symptoms so they and their families can focus on *"the meaning-making... growth and development that can happen in the terminal phase."* Although he is acutely aware that his job is *"to sort of get out of the way; it's not really about me... it's not really about my god like powers as a doctor; it's really creating the conditions for that stuff the patient and family have to do."*

Advocating for palliative care, Dr K cites the challenges he faces in the medical profession with an emphasis on curing and eliminating disease. He talks of his mantra, *"palliative care is active care"* informed by his belief that *"there is always something more that can be done"* for a dying patient. At times it is an almost contradictory context he navigates, when in some situations colleagues resist palliative care involvement and in others, his specialist knowledge means patients are readily handed over when a cure cannot be found.

*"Sometimes our recommendations are welcome and sometimes people get stroppy. There's a lot of relationships and you have to be collegial... But I have heard that they don't want to deal with palliative care... And we are in fact as specialist palliative care providers, we by definition, get the 'too hard basket' for a lot of other practitioners, that's part of the point of our speciality."*

Anticipating patients will want to talk about dying with him because he is the hospice doctor, Dr K is often disclosing not just a prognosis, but what dying will likely be. Sometimes it is in the privacy of a patient's bedroom when alone with a patient they ask *"the 'How long have I got, doc?' question, that's often, they don't want to ask that necessarily in front of their family."* Then because his practice extends beyond the patient to their family and loved ones, he will suggest to his patient they talk about those issues with their family afterwards.

He cites studies showing *"if somebody dies peacefully and the family are supported, there's less depression downstream, there's less complex grief."* Dr K considers this is a measurable outcome for palliative medicine. In the uncertainty of death, Dr K finds it reassuring for him and his patients, to anticipate what could happen and have a plan A, plan B and plan C. This process gives back some control to the dying patient faced with the wearying experiences of losses, *"chipping away"* at their life. Much of what Dr K seeks to do is try to re-frame the loss, as new achievable goals.

Dr K believes to work in palliative care *"you have to reflect upon your own mortality."* Experiencing the death of his older brother before he trained as a doctor is to this day something Dr K says is *"quite front and centre for me to*

*think about things.*” He shares the poignant story of his father, who was also a doctor, being told his son was dying:

*“The doctor who was looking after my brother came in and started to talk to my dad, because my dad was a doctor, she started to talk all the medical stuff about what was happening and my father stopped her and said, ‘I don’t need to know, I know he’s going to die, I don’t need to know this’. That stayed with me a long time, well till now. So I now I feel I can ask patients and families ‘how much do you want to know about what is happening’ because if they want to know, they will tell you.”*

In his teaching with junior doctors, Dr K talks of the centrality and inescapability of death, reminding them they will come across dying patients in every rotation. He challenges how death and dying is communicated; a staunch advocate of clear and unambiguous language, he implores his students, *“If you mean die, say die or dying; please don’t say ‘pass away’, ‘move on’, ‘time is short’, ‘things aren’t looking good’ or whatever the million euphemisms are.”*

Language and words are also an important part of Dr K’s meaning-making. Creative media are referred to often. For example, he talks of music shared with dying patients at the hospice and embracing the way other cultures deal with dying:

*“And the music that happens around here is also amazing because a lot of music happens, Māori-Pasifika usually. Somebody Samoan is here, choir comes in, they’ll stand around singing, it’s lovely, everybody loves it, patient, family, patient in the next room, family down the end of the corridor, staff, everybody loves it when it happens. It’s never intrusive it’s always pleasant.”*

He sees music as a very safe way for people to talk about death; *“everyone can think of a song that means something to them and they get tearful about this and that song, but it’s all kind of ok if it’s a song.”* What began as a self-reflective process; a way of *“dealing with things naturally”* grew into a way of communicating this message to a wider audience. A couple of years ago he organised a public event, with live music selected largely from African-American music he grew up with. For Dr K the lyrics of the songs he selected spoke of hopeful transitions in the dying trajectory:

*“For me, it’s my music and the songs about dying and grief and loss and healing and that was the important theme I wanted to get across in that concert that I organised was the trajectory to healing ‘when the doctors give up, the healing begins’ ...”*

When I asked what he would do if he was not doing his current role, he replied instantaneously he would do another concert, in America, and this time he would get funding to make a documentary of it. Dr K exemplified a vocational and personal commitment, fuelled by crusading enthusiasm for palliative care.

## Dr Z

As a senior radiation oncology specialist practising in the same city over the course of his extensive career, Dr Z's patients can span generations of the same family. The joy of the job for him is the relationships he has with his patients and their families. Making connections across families can be an opportunity to give back to patients and is a hallmark of his practice. On one occasion while looking at a patient's family tree, in a consultation with a woman concerned she was carrying breast cancer genes, Dr Z identified *"at least a dozen names"* of people he had treated. His *"peculiar brain"* meant he could recall for his patient particular memories of one relative whom she had only met once, facilitating a connection she greatly appreciated. Although he has a strong belief in the very good public health system, now working in a private clinic Dr Z feels he is able to offer a greater continuity of care, compared with the potential for disconnect in the public system where patients may be seeing different registrars at each appointment. Because of this continuity he feels his patients *"get to have a relationship that is almost like friends with a professional boundary thrown in."*

*"They know a bit about me, I know quite a bit about them which has nothing to do with their actual cancer journey but actually helps form a relationship so that . . . you can talk often a little bit more easily about bad news or a change that might be bad news, because you know a bit more about the patient or in particular you know a bit more about the patient's support systems and family."*

Despite a significant shift in survival rates from cancer illnesses during the course of his career, Dr Z still has many patients at any one time who are dying. With people living longer now and cancer more of a chronic illness he is always *"balancing the co-morbidities of the other illnesses in terms of [your] ability to withstand orthodox treatment of that particular cancer."* When patients are dying he is often having to delicately discuss early on treatment decisions to determine when interventions would be appropriate; something Dr Z finds easier in the context of a well-established relationship with his patient:

*"... you can have talks around, 'I wouldn't artificially resuscitate you if had a cardiac collapse and you were in the last week or so of your life unless you specifically said you wanted to be.' 'Oh*

*thanks, no, of course I don't.' 'But if you had an infection and I could treat the infection and get you back to the quality of life you had before the infection that meant that you're daughter can get back from London or something, it would be sensible to do that wouldn't it?'"*

Forming these relationships is facilitated by Dr Z's comfort communicating with people from diverse backgrounds. He attributes this to his formative experiences from his upbringing and his pathway to medical school:

*"I think that's one of the harder things for young doctors now because I was of that era where you had the holiday jobs and things like that which were for want of a better description, 'working-class' jobs, and we could get them. So I had five years in the freezing works, had a year off, a year at Certified Concrete, got landed in the territorial army... and I played a lot of sport so you come across all sorts of people... So I think that really, really helps and I wasn't bright enough to get straight into medical school so I did a science degree first, so I was probably a couple of years older as well... so I'd done a bit of growing up beforehand so it was a little bit easier."*

Similarly, limited access to diverse "*working-class jobs*" as holiday work for today's medical students concerned him. Dr Z is a strong advocate of the interpersonal skills needed to successfully treat patients, and suggests that even though today's medical students are "*much, much, brighter*" they are not necessarily the "*most rounded*" having "*never mixed up against the common man or woman.*"

Dr Z's learning experiences as a young doctor came from working alongside the "*grumpy old surgeon who might have been a bloody good surgeon but was absolutely useless at talking to patients.*" Interestingly, Dr Z has now treated some of those surgeons, one of them even thanking him for "*mopping up after him at the end of the ward round after me doing the wrong thing.*" To which Dr Z replied:

*"Well, you were shy; I could tell you were shy. He was the third generation of surgeons all with the same surname and my mother who was a nurse describes his father as exactly the same, grumpy and imperious, he was probably shy too, probably went to a posh, private school and didn't get taught any communication skills."*

He acknowledges medicine can be a tough profession where doctors put a brave face on their pain and grief because this was "*what they signed up to do.*" Dr Z talks of his own experiences of this when as an oncologist he is dealing with bad news most days. Characteristically, he believes the

*“gifts from patients being grateful or friendly or pleased to see me”* more than compensate and are more than many other specialists receive. He is not nervous talking about bad news or sad situations. He feels he is able to do it so that most of the time it’s a positive experience for the patient and their family, often resulting in getting a hug from everyone on their way out. There is a cumulative grief he feels from these situations, but Dr Z considers he copes because he has been able to contribute to helping his patients in their acceptance of dying and the meaning-making that can come from that for them and their families. No less emotionally expressive with age, he is comfortable showing sadness in front of patients and alone:

*“I still cry about lyrics and poems and bits and bobs and things like that, and that helps me cope with my day-to-day job when I can feel a bit moist eyed about something. But its okay, the true hurts gone because I’ve acknowledged what it means.”*

Dr Z receives gifts from patients, though he gives much in return. His care and abiding respect for his patients connect him to their humanity. He meets them as people and seeks to offer the best care he has available to nurture them through their cancer journey.

## Dr B

Dr B is a surgeon at an urban public hospital. He estimates up to seventy percent of his non-emergency operative work is in breast cancer surgery. For the purposes of the interview he selected to talk about his experiences disclosing life-limiting diagnoses to patients with breast cancer. His career as a surgical specialist has evolved alongside the growing trend toward medical specialisation in New Zealand. He considers this shift toward sub-specialisation is reflected in most international metropolitan areas and has emerged from the perception that *“the more you’re dealing with a given disease process the better you get at it.”* This context has facilitated Dr B orientating his surgical work toward an area of medicine that has aspects he likes:

*“There’s a lot of interplay with other departments, there’s a fairly high level of patient contact...and the other thing which is appealing is that for the majority of people, particularly with screen detection of the disease, the long-term results are relatively good.”*

Dr B reflected on whether he has gravitated toward this speciality because the interaction he has with patients suited his personality:

*“I think by the average surgeon’s standards I have pretty reasonable communication and interpersonal skills. And so therefore, is it*

*pure chance that I've ended up doing an aspect of surgery that has a pretty significant amount of patient interaction?"*

Describing the disclosure of a breast cancer diagnosis to his patients as a “*pretty natural conversation*” he strives to communicate in a straightforward and non-condescending manner the information he would want to know in the same circumstance. Uncertain how this can be taught, he considers learning how to disclose bad news to patients in medical school came at a time when as a student he had limited exposure to patients. Instead he referred to learning how to communicate on the job, ‘cherry-picking’ from the good and not so good styles, of senior clinicians, a mode of learning that continues with his current registrars.

*“I think they [registrars] do pick up by osmosis and when I look back on my training, I think you definitely get influenced by certain individuals, you get influenced by and you ‘cherry pick’; you see things that that person does quite well and that person does quite well, they don’t do this so well. But I think a lot of the training in terms of that sort of thing is probably by observation. Obviously personalities are different and there are some people who are better suited to the certain aspects of medicine than others.”*

He quips that in medicine for “*anybody from aspergers to extroverts there’s a job you can do and everywhere in between,*” but despite perceptions “*surgeons who can’t talk their patients aren’t generally going to be very effective in their role.*” Dr B believes people want a quality consultation with him, where they leave the consultation comfortable that they have “*a good handle on what the problem is, what the options are, and what the pros and cons of those options are from somebody who they think knows what they’re talking about.*” Appointments offer only a short space of time to achieve this, generally twenty to thirty minutes for a first consultation and ten minutes for subsequent clinic appointments. Dr B must be able to convey a lot of information to his patient so that he can move them toward a decision on the treatment options they are most comfortable progressing.

The pressures on these appointments mount when statistically the probabilities of survival are stacked in favour of early detection and treatment. Moreover, subsequent treatment such as surgery and radiography must be scheduled into a system that can become rapidly over subscribed.

Although rarely emotionally affected by the disclosure of a breast cancer diagnosis to his patients, Dr B says he no longer has the buffer of youth that helped him as a young doctor. He too has aged and is more conscious of his own mortality:

*“When you’re fifty-three and you’ve got a forty-two year old with breast cancer, you start thinking. I was sitting at a multi-disciplinary*



*meeting the other day and I was looking down the page at new cancer diagnosis and I made the observation that I was about median age of the women we were discussing and you think [hesitates]so I think it changes.”*

Although he has a lot of “*stop and sniff the roses moments*,” he is mindful of the need to have clear boundaries between work and home:

*“I think the other thing is too when you’re driving home from work at the end of the day then you have got other things, work is part of what you do but for me I’ve got kids to get fed, homework done, bathed and into bed, school lunches ready for tomorrow or whatever, you’ve got other family issues or other things. I think if you take it home with you then you’re a time bomb waiting to go off.”*

## Dr V

As a doctor specialising in hospital-based palliative care, Dr V’s experiences of death and dying are extensive. He now heads up the palliative team in a public hospital that provide advisory services to a broad constituency of patients and staff. Although in this capacity, he is often not the frontline person who is formally tasked with disclosing a terminal diagnosis to a patient, he is the person who frequently has to re-communicate the ‘bad-news’; exploring what the reality of that diagnosis means for the person and their loved ones. He is also charged with leading the teaching, support and advice to staff handling death and dying.

*“So we see people on surgical wards who’ve got surgical problems, who’ve got medical problems, who’ve got cancer related problems, non-cancer related problems, we see people who are in their teens to people who are in their hundreds; well early hundreds... we see people in intensive care, we see people in the emergency department or just on the regular wards.”*

The service provided is largely advisory, meaning Dr V and his team are called in to assist and work alongside other medical teams:

*“So they’ll say, ‘Dear palliative care team, please could you see this patient that we’re looking after who has got some pain because of their cancer and is also struggling to come to terms with what’s going on and can’t make decisions about the future,’ or ‘the family is fractured and falling to pieces, can you please help give support?’”*

This is a shift in how dying patients have been cared for in the past and it is relatively new to have a palliative care team in a hospital as *“hospitals have been a bastion of cure-based treatment and always doing something to try and stave-off disaster.”*

Working in this area long-term, Dr V’s insights and experiences have shaped his meaning-making of seeing both patients and staff act as they do in the face of imminent death. He considers the praxis of his own beliefs in how he supports patients and colleagues. His narrative is temperate and philosophically informed.

Dr V was conscious and expectant of death as a natural outcome in medicine, though he found little support in his training that enabled him to extend the physical manifestations of dying to the emotional realities for patients and their families. At the end of medical school and a few years working as a general physician, Dr V decided to train in palliative medicine offshore and in New Zealand.

He believes people usually die much as they have lived. For some *“that sense of who I am, of meaning, of meaning-making, of trying to put things into context”* is extraordinarily important and for others *“it’s just not.”* He has witnessed many people dealing with their imminent death:

*“Some people will have conversations that lay things to rest and patch-up wounds and patch-up rifts. Many people won’t. This idea that you approach death in the same way and that it’s necessarily healing or transforming or forgiving or whatever, I think that they’re hopes and wishes that society put on for us to see that there’s some good that comes out of dying.”*

For him, striving for the good death may be the goal of many, or the need of society, but the reality he sees is that many patients experience *“a good enough death.”* The experiences of working with dying patients can be many things for Dr V:

*“... it can be uplifting, it can be sad, it can be depressing, it can be engagingly interestingly, fascinating. There’s a range of things and it’s often a mixture of a lot of that. And it can be confronting. It can be motivating for you to kind of think about your own issues. It can be challenging as you try and work out what your issues are and what actually are the professional issues which I think is a core piece of work that needs to be done if you’re going to be in this work.”*

He is concerned for his colleagues who suffer when they are unable to express or share the grief they feel from continuously dealing with difficult deaths. Dr V believes this can lead to clinicians detaching the patient as

person and ultimately to their own burn-out. He practices mindfulness; trying to be in the moment and stay aware of his own issues coming up from what is happening for his patients. He cautions that without this self-reflection, many clinicians risk treating patients based on what they would want for themselves or their loved ones and not what is necessarily best for the patient. Dr V is aware of the pressures inherent in the medical system which contribute to clinician's feeling more intensely a sense of duty to leave things behind at work. The challenge is to work out how:

*"I guess part of who I am is a doctor; part of who I am is a family man and a lover, a person who has an unhealthy interest in good food (laughter). That is who I am so I can't pretend that the times where who I am is not the doctor part of me but on the other hand I can leave behind my feelings that I constantly need to be there or that I am constantly responsible which I think was difficult when you first start with many clinicians because you think it's your duty. So there is a duty but the duty does not interfere with your right to have privacy, to be able to leave it behind and say, 'I'm not responsible anymore.'"*

Leaving work each day, Dr V often touches a pounamu at the entrance of the hospital *"to just leave my hospital self behind in that act, so there's almost like a ritual about that."*



## Chapter 6

# Telling

### Introduction

*“Diagnosis remains a ritual for the disclosure: a curtain is pulled aside, and uncertainty is replaced-for better or worse-by a structured narrative”. (Rosenberg 2002, p. 255)*

I began this research wanting and expecting to hear what it was like for clinicians to tell their patient they had a terminal diagnosis or prognosis. What I learned in the process was the experience of disclosure for clinicians was less distinct. In the initial analysis of the clinicians’ experiences of disclosure three themes emerged that provided a critical context to further analysis. All of the themes resonated with the literature regarding the ongoing debate about truth-telling by medical practitioners.

The first of these was locating the act of disclosure within the clinicians’ narrative. When I asked the clinicians how they experienced disclosing to a patient that they had a potentially life-limiting illness, their initial responses revealed how indistinct the act of telling can be. Some responses appeared diffuse and were conditional on where they were positioned within the structure of specialisms in medical care, if other medical practitioners had or had not already disclosed a diagnosis, if they consider it was their role to tell, and if the patient had understood what the disclosure meant.

Initially I mistook this as an evasive response to discussing death and dying. However, all of the clinicians were unequivocal in providing patients with the truth about their diagnosis or prognosis. It became clearer in the analysis this process of orientating the ‘telling’ to a specific situation was indicative of the context within which disclosure occurs. Some of the clinicians’ experiences reflected a blurring of the boundaries evident in the research literature, such that it was not always clear to them who was responsible for telling the patient, or when they would receive the diagnosis and when they did, how quickly to disclose this to their patient.

For example, Dr X recalls when a radiologist phoned her with the results of a mammography report for a patient that “wasn’t really mine.” When she enquired who was going to tell the patient a lump had been detected, it seemed no one was taking responsibility for this:

Dr X: *“Then the mammography people rang another doctor, not me and said, ‘There’s a lump under this woman’s arm.’ And this doctor passed it on to me and I’m going, ‘well are they are going to amend the mammography report or are they going to write a letter about that?’ No. So this information wasn’t told to the patient, came to me via somewhere else and then the thing was well . . . I’m like this is so strange, what do you do with that?”*

Similarly for Dr B, some of his patients were told the results of a needle biopsy for breast cancer by their GP, however he could never be certain how the disclosure was communicated:

Dr B: *“Yes, what you’re never quite sure is with their GP how the diagnosis has been couched. What I would hope is that if they got a biopsy identifying cancer then the GP would have told them they had cancer but I think occasionally it gets couched in slightly fluffier terms to just ease them in gently to the diagnosis.”*

Experiencing other clinicians struggling or avoiding telling patients clearly and unambiguously their diagnosis was life-threatening was commonly cited by the clinicians. Dr V offers an explanation for this that empathetically situates this sense of avoidance within a context of the clinicians’ fear they may hurt their patient:

Dr V: *“And so I’ve gone from, ‘Oh gosh, if only they’d done it this way’ to just acknowledging we’re all human (laughs) and that’s just the way it is and these are hard, hard conversations for people to have and to deal with, that people don’t want to do this, they feel that they’re going to hurt someone by giving the news or they’re going to take away their vestige of hope in the future, that they’re going to damage them in some way and so these are protective, maternal instincts that kick in.”*

The risk of harming a patient as a barrier to full disclosure along with the fragmentation of medical care into bounded specialities, these examples from the clinicians’ experiences are commensurate with the literature on the complexities of what is truth-telling. Contextualising the clinicians’ experiences within these complexities highlights how judgements of clinicians’ as lying or withholding the truth can be misinformed.

The second theme was the centrality of the process of diagnosis to the clinicians' experiences of disclosure. I had expected the technical diagnosis to be a cleaner and bounded platform from which the experience of telling their patient would begin. However the analysis brought forward narratives deeply embedded and entwined in diagnosis as a temporal process influencing the professional presentation of disclosure. In this way, working from their "medical narrative" diagnosis was often the starting point for the clinicians telling me their experiences of disclosure (Brown, 1995, p.39).

Closely aligned to the process of diagnosis and the third theme prominent in the analysis was the clinicians' experiences of disclosure as a process rather than a penultimate moment of telling. Of interest is what appears to be a contradiction in this position when single moments of telling can be identified in the clinicians' stories. This suggests the intermediary position offered by Willig (2011, p. 898) of "crisis points" which punctuate the "cancer journey" may be a more helpful depiction for patients and clinicians.

In this chapter I present three clinicians' stories of their experiences disclosing a potentially life-threatening diagnosis to their patient. Using narrative analysis I consider these stories as illustrative of the themes outlined above. All three stories provide an insight into the centrality of diagnosis to the clinicians' experience of disclosure as a process within an anticipated trajectory of medical care that would follow the disclosure. However, what also emerges from these stories is that within the process of disclosure lies the potential for the act of telling to be difficult to locate in the fragmentation of medical care.

The first story from Dr K tells of a "textbook" diagnosis of pancreatic cancer and the disclosure to his patient. Dr K's diagnosis narrative depicts how disclosure can be indistinct within a patient's medical journey despite his own determination to always tell the truth to his patients. Following this is the second story from Dr B of diagnosing and disclosing breast cancer to patients. In this story the impact of improved survival rates can be seen to influence the disclosure experience. With confidence breast cancer detected early can be successfully treated, the disclosure of the cancer diagnosis is focused on the treatment actions to follow. In contrast to the more clear-cut diagnosis and disclosure in the narratives of Dr K and Dr B, the final story from Dr X speaks of the uncertainty of diagnosis and the dilemma of when and how to tell a patient the results of their biopsy.

Analysing the clinicians' experiences of disclosure in this chapter I also identify themes explored more fully in Chapter 5 such as the impact of the organisation of medical care on the experience of disclosure for the clinician, the intensification of time with the focus on treatment following a disclosure and the expectation of patients to respond positively to the treatment offered. In this way, the narratives of diagnosis that follow provide a foundation for the analysis presented in Chapter 5 of how the clinicians' experiences of disclosure are influenced and in part managed, by the culture of the medical profession.

## Narrative 1: Dr K

When I arrive down a sweeping driveway for the interview, Dr K greets me, guiding me outside to take me on a tour of the hospice. It is an impressive site nestled within lush grounds. I notice balloons swaying and tinsel glinting from a modern building nearby. Dr K tells me they are celebrating the opening of the building today, the result of a long battle to provide rooms for art, music and counselling therapies. He proudly leads me through the building, introducing me to staff and hospice volunteers, telling them he is being interviewed. Leading me back into the main building, we traverse further site works as he explains the extensive retrofit underway. Eventually we settle into the library, seated at an antique table over cups of herbal tea.

Dr K speaks rapidly as his voice undulates with intensity and animation. He is passionate about the palliative care movement. It infuses the experiences he speaks of and is a place he returns to frequently in the interview. During the interview he determined that the central theme of my thesis was communication. He actively sought to reframe and re-position my research responding to questions with narratives on communication skills and techniques:

Dr K: *“So my own teaching now, it’s like, you know, it’s . . . lead with your big, your first message, don’t beat around the bush. Lead with your first, well ask what the patient wants to know, then lead with your first message and then stop talking.”*

While I agreed this was important, it was as if we batted the ‘experience’ question back and forth. I sought his opinion about the experience more indirectly, referencing literature that discusses the patient’s experience of the moment of being told the diagnosis as the beginning of other processes.

## The Textbook Diagnosis

We talk about the diagnosis process and Dr K tells this story of his experience of what he describes in the opening line as a “classic” medical case:

*“Dr K: I had a classic,  
out of the book,  
probably my third day in general practice when I took over from  
this retiring GP.  
Fifty something year old guy comes in,  
he was a professor at the University.  
Patient: “My wife says my skin is turning yellow.”  
Dr K: “Oh do you have pain?”*



*Patient: "No"*

*Dr K: Now in my textbook*

*painless jaundice equals cancer of the pancreas*

*so in thirty seconds I'm thinking he has cancer of the pancreas,*

*and I need to do these blood tests*

*and I need to check and get an ultrasound and you know, things. . .*

*so I have to address that with him, I say, look at him:*

*"Actually your skin is turning yellow; this is the list of possibilities"*

*Again it's not a definitive diagnosis right?*

*He's got these symptoms,*

*I'm telling him this is high on the list of possibilities, cancer of the pancreas,*

*but to him, that's sort of a shock*

*and I don't remember that he was particularly upset or distressed or shocked,*

*- he wanted the plan."*

Dr K enacts this story as a scripted play, a feature of his narrative and story-telling throughout the interview. Choosing to tell this story largely as a dramatic presentation has the effect of collapsing time as if the diagnosis is happening in the present (Riessman 2008, p. 109). Employing the genre of performance, Dr K gives lines not only to himself but to his patient (Riessman 2008). The use of direct speech is a narrative feature that Riessman suggests "builds credibility and pulls the listener into the narrated moment" (Riessman 2008, pp. 112–113).

Dr K describes this medical case as a "classic" and I wonder why he uses this term. Is the case an exemplar of pancreatic cancer or does this evoke a sense of a routine, conventional diagnosis? Perhaps it represents the medical story ingrained from medical school, where students learn to determine what counts as valuable information and how to present that convincingly as the case history and differential diagnosis (Becker 1993). Dr K's narrative is ordered as a medical story and as he knows I am not a doctor, he provides a lay person's description of the symptoms. The almost immediate diagnosis conveys skills learned as a junior doctor seeing patients with the same symptoms and over time being able to position them along a "continuum of illness." This knowledge is evident in Dr K's reference to "his textbook" which offers an additional mark of competence and demonstrates the integration of his early learning from medical textbooks to his own body of knowledge.

As the diagnosis unfolds, there is a sense of urgency when Dr K, recognising the symptoms of a potential cancer, propels his patient toward a life-changing

diagnosis. Time intensifies his need to prepare his patient for the interventions required to confirm the diagnosis, reminiscent of the “ritual of intensification” Chapple (2010, p. 89) describes.

In an ‘aside’ to me, his audience, Dr K tells me this is not a definitive diagnosis but is an example of how the disclosure of a potential terminal diagnosis can quickly avert to the focus on treatment (Riessman 2008, p. 112). It is as if he has in effect “brokered” his patient’s part in beginning the journey toward a medicalised future (Timmermans 2005, p. 993).

Dr K acknowledges this is a shock for his patient though he does not recall his patient was upset or distressed. However, introducing their shared identities as professionals into the narrative, Dr K seems to align them both with the expectation of a rational, pragmatic response to the diagnosis. Dr K is understandably anxious to facilitate confirmation of this diagnosis as quickly as possible though it may be this focus on immediate issues is indicative of research findings which demonstrate how this moves the discussion away from acknowledgement of the possibility of dying (Anderson, Kools, and Lyndon 2013).

His patient wanted “the plan,” indicating emotional responses were neither appropriate at this early point in the diagnosis nor helpful when there was a fight to prepare for. Yet, the patient literature of the disclosure processes that begin with those first initial references to cancer, can tell a different story, illustrated graphically by sociologist, Ian Craib (2003), in his personal experiences of the diagnosis of a brain tumour:

*“From the moment that the words ‘brain tumour’ were used by my GP to the confirmation of the diagnosis, I was all but paralysed by what I would then have called intense anxiety. When the diagnosis was confirmed, the anxiety took off its mask and revealed itself to be abject terror, a fear I had not felt before and which has haunted me ever since, appearing now and again despite my efforts to submerge it in everyday routines (Craib 2003, p. 286).”*

Was Dr K’s patient also paralysed with fear? It seemed he would not have been expecting the likelihood that he had pancreatic cancer, nor may his wife when she mentioned his skin changing colour. With the patient’s potential anxiety in mind, I wondered if Dr K had considered waiting until diagnostic tests had been completed before opening his patient’s world to the potential for the haunting terror Craib (2003) experienced.

*“Jo: So when you’re in that situation, a situation like that, the options could be to not say anything and do the tests and then...?”*

*[Cuts across quickly]*

*Dr K: I would never do that!*

*Jo: OK*

*Dr K: Never do that.*

*That to me flies in the face of good patient/clinician [...]*

*I mean that's early on in the piece for that man*

*and of course if he said, 'How long have I got doc?',*

*then it would not have meant anything because it didn't have any exact diagnosis*

*all the way along.*

*I think it's really important to be clear*

*and assess the understanding of this person you're talking to."*

The question prompted a vehement response. Dr K interpreted my question as a suggestion that he withhold information from his patient who he had assessed as being able to understand the diagnosis and what it may mean.

Dr K's story continues on to describe the actions that follow this initial diagnosis. He describes a series of events; tests, scans, operations and further diagnostics to portray an evolving process of moments of disclosure leading to a final confirmation of the disease as terminal. In the passage that follows, Dr K summarises the possible ways, "the moments", when his patient may have come to an understanding of the diagnosis of pancreatic cancer that followed his initial diagnosis:

*"...but where in that process did he think,*

*or who had the conversation with him, that said,*

*'You're not going to get better from this'?*

*Wasn't me;*

*probably was oncology that had that conversation with him*

*that there are no further chemos that we can offer or whatever.*

*But he would have had a conversation beforehand from oncology which would have said,*

*'We're going to try this chemotherapy which has a fifty percent response rate'*

*or whatever.*

*And then how much understanding did he have?*

*He was a scientist so probably he could understand*

*except it was him personally so maybe his understanding*

*wasn't being so quite scientific*

*when an oncologist talks about those kind of numbers and percentages.*

*So probably it's a long, drawn-out moment of realisation,  
that actually this is not going to get better.*

*So in those studies that you're reading what is being reported by  
the patient?*

*Is it that moment that they figured it out?*

*Or is it the moment, and probably a variety,  
but it could be that sort of,  
this is not going to get better?"*

In this narrative Dr K depicts the many junctures of diagnosis and possible disclosure moments leading his patient to a final terminal diagnosis. His immediate diagnosis of his patient's symptoms is removed from the sequence of events. It is at these junctures of diagnosis moments where ownership of disclosing the diagnosis to his patient shifts and is diffused by, the specialisation of medical care. The "ritual of intensification" is renegotiated in Dr K's story and the cultural scripts shift with a renegotiation of the goal of care. Gradually care is reformulated away from the intense battle when hope for recovery is abandoned toward "comfort care" (Chapple 2010, pp. 89,187).

Despite decades of open disclosure policies, and Dr K's position of telling his patient the truth, in the process of treatment he assumes the patient will discern his own awareness. Dr K is unable to pinpoint a time when a medical professional in this illness trajectory told the patient he was dying. The gradual awareness he anticipates his patient coming to, in figuring out over a long drawn out process, he is dying, mirrors the gentle, managed and peaceful acceptance of death and dying in hospice discourses. Dr K's assessment of just when in the unfolding process of disclosure his patient knew he was dying speaks to the "gradation of the awareness contexts" Timmermans (1994, p. 332) identifies in his research. Here there seems to be an "uncertain open awareness" where clinicians remain the "gatekeepers" of information but may be holding back on the full account or softening the information to maintain the patient's sense of hope (Timmermans 1994, p. 332).

Dr K's approach of advocating open awareness at the earliest moment of his symptomatic diagnosis but not locating a moment of telling in any future diagnosis appears contradictory. It seems his patient is returned to a mortal being in the absence of a successful treatment and all responsibility has been divested to him to "figure it out". Chapple (2010, p. 89) suggests this is a way to maintain our faith in medicine when it fails others:

*"This effort preserves the integrity of the medical project as it rubs  
up against the margins of death. The ritual maintains the illusion*

*that death comes only as the accidental convergence of this particular set of circumstances. The rest of us might still be exempt."*

Later Dr K tells me he was at his patient's bedside as he was dying suggesting the continuity of the relationship with his patient is restored. In this transition or liminal period, Dr K can be considered to have taken on the role of "master of ceremonies" charged with guiding his patient to the closure of the ritual, which ends at the deathbed (Boland 2013, p. 230). Patients in hospice care also return to Dr K in their transition, or liminality, toward death:

Dr K: *"I had a patient who died of a pulmonary embolism, very classic, she'd been on the loo, she said to the nurse 'oh', she felt something change in her chest, not particularly painful, but she suddenly said 'I don't feel very good at all', so the nurse helped her back to bed and called me and I came in. She looked at me and she said 'Am I dying?' no she said, 'Am I dying right now?' and I said 'Yes, you're dying right now'... and she died within a minute, probably the whole thing was probably five minutes from being on the loo to having died."*

In this account, Dr K provides a story of another "classic" case. His use of the word classic in both stories emphasises it is the nature of the experiences that stand out for Dr K and that is why they are important to tell. Both stories make a point of Dr K's unambiguous commitment to telling his patient the truth, right to the end. Both stories are also told to highlight how Dr K experiences disclosure as moments within a process of diagnosis and prognosis. When it is deemed to be his responsibility to tell his patient he does but he cannot determine how disclosure will be managed by his colleagues despite his best efforts to improve open and full awareness in his own teaching and practice.

## Narrative 2: Dr B

In the next story a similar pattern of diagnosis as Dr K's pancreatic cancer patient is retold. However unlike Dr K, Dr B describes a hypothetical patient and begins by orientating to the context of the diagnosis, so that it is clear this is a patient he is seeing for the first time. This sets the scene for the clinical encounter. He does not describe the patient but she is present as he elicits her symptoms and information about family members. Interestingly, many women Dr B sees have no symptoms but because of their age or other determinants, they are assigned a risk profile and invited to a screening programme. In this way, the categorisation of his patients is an example of the "pre-disease identification" Jutel and Nettleton (2011, p. 795) describe in their research

within the sociology of diagnosis. The effect of this is to blur the boundaries of disease diagnosis, creating what they describe as “a temporal and spatial fracturing” of the diagnostic category (and the diagnostic process).

The hypothetical story evokes a sense of routine and familiarity for Dr B as he describes the clinical approach to getting to a diagnosis that will announce the presence of breast cancer. Like Dr K, he is clear of his role in the disclosure process and does not avoid telling his patients the outcome of the diagnostic tests they have undergone. He too experiences disclosure as a process which initiates the pathway of treatment and further testing that follows for his patients. It is also in Dr B’s narrative where the impact of significant shifts in survival rates for some cancers can be seen to influence his experience of disclosure.

### The Point Where You’ll Know

I met Dr B in the midst of a busy outpatient clinic of an urban public hospital. He finds a spare room and ushers me in. It is not his office but a consultation room. I have to remind myself I am not here to understand how his patients might feel as I try to work out which of the chairs to sit in that are lined up next to his desk. It is a tired interior and I find it hard to adjust my vision to the stark fluorescent lighting overhead. I get the sense that time is precious as I organise myself to begin the interview.

In this excerpt, Dr B describes a series of possible steps in the diagnosis process which leads to the clinical encounter where he is communicating a diagnosis of breast cancer to his patient for the first time. They are “newly diagnosed” patients. He tells this in response to my interest in how he prepares for the disclosure conversation with his patients.

*“If I’m seeing them for the first time,  
then I’d take the history in terms of what symptoms they’ve had  
any risk factors they might have,  
like a person in the family history with breast cancer,  
normally I’d check out their relevant medical issues  
that might be germane to management of the breast cancer,  
do a physical examination,  
show them the mammograms that they’ve had done,  
pointing out what their abnormalities are  
and then talking about the result of normally a needle biopsy  
which has confirmed the breast cancer  
and then with that*

*run through what are the options.*

*So at that point they'll know,*

*'you've got breast cancer.'"*

Like Dr K, the presentation of the patient to me as a case is integral to the medical story in Dr B's narrative. Disease is the 'object' and the person is the site of the disease, not as a "narrative agent" of their illness (Good 1994, p. 80). The passivity of his patient is interpreted through the actions he ascribes to himself. He sees the patient, takes their history, checks out relevant medical information, does the examination, shows the mammogram, points out abnormalities, talks about results, and runs through treatment options. The results of this are two-fold; "the inattention to the lifeworld of the patient... and what we know as routine, rational medical practice" (Good 1994, p. 80).

In the temporal ordering of this disclosure 'routine', announcing the diagnosis of breast cancer is only offered at the end of the consultation that culminates in the mammography results as irrefutable proof. Dr B's narrative mimics the structure of disclosing a breast cancer diagnosis to women for the first time that Taylor (1988) identified in her research. Dr B begins the conversation with a preamble to "set the stage", leading to the "confrontation" – in this case the confirmation of the breast cancer diagnosis, followed by "diffusion" where discussion shifted toward medical interventions which Taylor contends is designed to lessen the impact of the diagnosis (Taylor 1988, pp. 116–117).

This diagnosis is early into a trajectory of care delivered by Dr B with "curative intent." He cites statistical evidence of highly successful outcomes when breast cancer is detected early such that the threat of the disease as life-limiting is rarely considered and therefore overt emotional reactions from his patients are unexpected. He experiences most of his patients' reactions as "appropriately upset or pragmatic" and it is "very uncommon to get people who are not emotionally and psychologically coping with it." Like Dr K, the focus is on the plan of what next:

Dr B: *"I think what people want is a quality consultation from somebody who they think knows what they're talking about, that they trust and who talks to them in words they can understand. So that they leave the consultation comfortable that they have a good handle on what the problem is, what the options are and what the pros and cons of those options are from somebody who they think knows what they're talking about."*

Again, however there is evidence in the patient literature that describes the experience of being diagnosed with breast cancer that is absent in Dr B's account of his patients reactions. The possibility for much more than a

stoic emotional response occurring for the patient is powerfully told in this evocative description of one woman's experience of receiving a breast cancer diagnosis:

*"I shut my eyes and saw absolute black, no lines of red or purple, pure black. My agitation lifted me off the table and I started walking around the examination room in small steps, working off the tension. I thought I might put my fist through the wall. And then when I opened my eyes, I couldn't see too well. Or hear too well either (Rosenblum in Frank, 2004, pp. 14-15)."*

The stark contrast of this story to how Dr B experiences his patients' reactions resonates with the literature that suggests patients emotional responses can be influenced and redirected toward the rational and pragmatic by the clinician's approach (Kaufman 2006; Maynard 2003). Unlike the "graphic moment" retold in this patient's account, in his narrative, the main event for Dr B is not the disclosure, but the application of his technical skills as a surgeon in the fight to eradicate the disease (Maynard 2003, p. 12). It is here where he can offer the most help to his patient. In this respect when Dr B delivers the diagnosis it is the preliminary to the "medical project" unfolding in the next part of the narrative, in which he must broker the medical interventions necessary to complete the project (Chapple 2010, p. 89).

Following disclosure his patients are engaged in decisions on treatment and the surgical option they prefer. There is an intensification of time reflected not only in the same fast tempo Dr B uses in the first story, but also how the narrative is structured (Shim, Russ, and Kaufman 2006; Chapple 2010). Dr B works from one action to the next suggesting a routine he performs in a time-bound process to ensure his patients have the greatest opportunity for survival:

*"So it's either going to be when I'm seeing them with their cancer diagnosis,  
there is nothing else to do,  
there's a discussion around treatment options,  
there are no further tests that have to be done  
and then I'll plan to see them again in a week to ten days  
to finalise what is their preference.  
Or, 'yes you've got a cancer  
but there's a few other loose ends we need to tidy up',  
get these further tests done  
and see you back here with the results of those*



*and then we have further discussion around treatment options,  
so we then say, 'This is the operation we're going to do'  
and then we go and do it.  
So I see them obviously when they're having their surgery...  
and then I'll be seeing them in the clinic normally about seven to  
ten days later  
with the result of the microscopic report on everything that's been  
removed."*

The patient's voice is still absent though there are discussions of treatments which lead to deciding what operation will be done. Dr B's use of the pronoun 'we' is used when he talks of the journey the patient is on with him. He refers to 'we' again when he talks of the operation that seems to indicate this is not something he is exclusively responsible for.

He returns to the first person in the next two actions, when he will see his patient at the time of surgery and in the future, following surgery. This next clinical encounter is another moment of disclosing the diagnosis to his patient. There are four times in this process where he is seeing the patient with gaps of seven to ten days, until she receives the final diagnosis. For Dr B there is a predictable process he can rely on to manage how and when information is disclosed to his patients with consultations embedded within a series of other consultations, similar to the "folding machine" described in the literature by Jespersen and Jensen (2012, p. 348).

All of this activity is again leading to confirmation in the form of the histology (microscopic) report, which offers a reading of the 'fine print' at the cellular level of his patient's body of "some indication of 'what does this mean?'" This is not "what does this mean for you existentially" or "how will this affect your lifeworld", but what does this mean for how the disease will be treated in an ongoing medicalised future. Focusing on "narratives of immediacy" averts discussion of his patients' lifeworlds away from the clinical encounter (Good 1994, p. 858). Each time Dr B meets with his patients in this schedule of consultations and treatments they are drawn back into this "therapeutic housekeeping" (Good 1994, p. 858).

This is reminiscent of Heidegger's use of the medical clinic as an example of a technology that transforms its patients (and its professional workers) into objects for inspection, "subordinate to the orderability of the clinic" (Frank 2004, p. 28). Dr B's experiences of disclosure are mediated and distanced by the patient's trajectory of care. The overarching structure of the medical system defines the time he has available for the diagnosis process and facilitates control over the disclosure processes. There is the impression of how each of the diagnostic actions he describes is arranged into a schedule of work tasks repeated for multiple patients over a longer cycle of outpatient consultations

and surgeries. Information is updated, incrementally at each stage allowing time for Dr B to prepare how he will manage the encounter.

### Narrative 3: Dr X

In the final narrative, Dr X retells the difficulties she experienced disclosing a skin cancer diagnosis to her patient. Similarly to Drs B and K, Dr X's narrative points to the impact of the structure of medical care on the disclosure process. There stories diverge however when Dr X is unable to know with the same certainty as Dr B when she will receive the biopsy results and therefore be able to plan for communicating these to her patient.

Dr X's story also brings to the fore the power of the clinician as "gate-keeper" to the disclosure of a terminal diagnosis or prognosis in that ultimately the decision to tell, when and how much to tell, remains with the clinician (Timmermans 1994, p. 332). This narrative depicts the dilemma of knowing when to disclose information to a patient, particularly when the patient's own "lifeworld" is considered (Barry et al. 2001). In this way, the questioning of the disclosure process by Dr X contrasts with the more indubitable responses from Drs K and B and begins to open up the analysis to the tension of personal and professional expectations of how disclosure is managed.

### The Uncertainty of Disclosure

The interview with Dr X is at the public hospital where she works in another role from her part-time general practitioner position. Within a few minutes of my arrival, she emerges before me. My immediate impression is her clear sense of self and defined style in contrast to the somewhat doleful institutional environment she is located in. She leads me through smoke stop doors and along a corridor into a secure part of the building. We enter her office and I am immediately struck by the many disorderly piles of papers occupying much of the long desk I am seated beside. Dr X folds herself onto an office chair, tucking her legs under her, settling into the conversation that easily unfolds.

This narrative from Dr X's interview came after she had shared experiences of disclosing terminal diagnoses to patients as a medical student and more recently as a general practitioner. Dr X describes her experiences diagnosing and then disclosing to her patient that a lesion on her leg is a melanoma. She begins this story relating her patient's gender and age with herself and through sharing these characteristics indicates the possibility of her connection to this patient and a strong sense of ownership in what follows:

*"I had a woman recently who was the same age as me  
and maybe that brings up some sort of transference kind of thing,  
you know?"*

*And she came with a lesion on her leg  
and she told me it had changed over a couple of months  
and I looked at it and I said, 'I have no idea what it is,  
doesn't look like anything nasty but the only way we can tell is to  
take it off.'  
Anyway she books in, I think about probably a whole month later  
to have it taken off.  
She has it taken off  
and it turns out to be a melanoma."*

Here, Dr X draws on the psychological terminology of 'transference' to describe and possibly explain her emotional experience with the diagnosis. Transference, or "the unconscious redirection of feelings from one person to another", in Dr X's narrative suggests a more direct acknowledgement of the medical profession's "signature rule" where emotional involvement with patients is against the rules (Sullivan 2009, p. 522) (Kasket 2006b, p. 143). Orienting to transference early into the narrative offers a sense of Dr X's awareness and centrality of her emotional labour in the clinical encounter compared to both Drs K and B. However, her concern that these feelings for her patient may be against the rules is suggested in labelling them as a professional transgression of 'transference'. In this way, Dr X demonstrates her internal "emotional supervision" of the professional norms and expectations of her as a medical professional (Kasket 2006b, p. 130). A tension arises because the emotional supervision is added to the story after it has happened, leaving me wondering if on reflection Dr X felt she had been too emotionally involved.

On receiving the pathology results, Dr X considers how her patient will feel receiving this news and is concerned she will have been waiting, in the "absent times" between consultations to hear (Jespersen and Jensen 2012, p. 346). Dr X situates the disclosure directly within the temporality of her patient's lifeworld and unlike Drs K and B, questions what her patient will need and what it will be like for her hearing this diagnosis. There is no contention from Dr X she was disclosing a life-limiting disease to her patient, or that this would be experienced as a single moment of telling for her patient. Although she knows it would be far preferable to see her patient and disclose the diagnosis face-to-face, her attention to her patient's lifeworld leads her to immediately contacting her patient by phone. Anxious that it is the end of the week, Dr X is conscious if she does not tell her patient immediately it would be another two days before she would hear the results.

When Dr X rings she ends up talking with the woman's daughter because the woman has taken a holiday. Inadvertently she introduces herself as "*Dr X from the medical centre*", realising immediately that now the daughter may tell her mother that she has called. Worried that if this happened her patient

may not be able to get hold of her and would be more anxious, Dr X decides she must now call the woman on her mobile and talk with her. She calls her patient and advises her of the diagnosis. Later in the day, concerned that the woman, having now absorbed the initial diagnosis may have more questions for her she calls again. Dr X does not want her to have to wait until Monday for answers. Despite her best efforts, Dr X feels she has failed:

Dr X: *"I didn't do a good job, well about the whole thing because sometimes when you try and do something well it seems to be far worse."*

In Dr X's narrative diagnosis is performed through a similar process as Drs K and B. The hermeneutics of her clinical interpretation begin with the experiential text of her patient describing the changes in the lesion, followed by her own reading of the physical text when she looks at the lesion. She is unable to finish reading the text without referring to the instrumental text (Leder 1990). Here, there is a similar distorted separation of the physical body from the diagnosis that is evident in the needle biopsy Dr B refers to. Parts of the women's bodies are extracted for an examination that is independent of both the clinicians and their patients, yet the women are still connected to this process because the specimens from their bodies are present in the reading of this text.

Similarly to Dr B, Dr X refers to the time of each diagnostic stage, from her patient's awareness of a change in the lesion over two months, to the removal of the lesion a month after the initial diagnosis. In contrast, Dr X's initial diagnosis did not generate the "ritual of intensification" as it had in the narratives of Drs K and B (Chapple 2010, p. 70). Retrospectively telling this story, Dr X knows the lesion is diagnosed as a melanoma, so her emphasis on the month long period before the lesion is removed shifts from the first encounter where it seems there is little to be concerned about to an emphasis on her patient's decision to book in "a whole month later." Dr X's patient had come to understand through the language of medicine what is expected of her and how to feel when Dr X did not raise immediate concerns about the lesion, other than as something to be removed in the future (Timmermans 2005; Shim, Russ, and Kaufman 2006).

Dr X does not say she removes the lesion, only that her patient booked in again to have it removed which appears to distance her from the unexpected diagnosis of a melanoma. This first section has set the scene for Dr X to unfold the difficulties she experiences with this diagnosis process.

*"And then that's where some of my difficulty comes from  
because then it's like should I have done something different about  
that?  
If I'd suspected it was anything else clearly*

*I would have suggested that she got it off earlier  
but it actually turned out to be a melanoma.”*

In this section Dr X opens out the difficulty she experiences when she begins to question how she could have contributed to a different outcome for her patient. In questioning her actions, Dr X reflects on the timing of the removal of the lesion and her professional responsibility for contributing to the delay. Unlike Dr K, the initial diagnosis does not lead to Dr X confidently determining the likelihood of cancer and therefore being able to prepare her patient for this possibility. Ultimately she cannot determine her patient's actions though there is definitely a suggestion that she thought she could have exerted greater influence to have the lesion removed earlier. Seeking counsel and support, Dr X discusses this with her colleague who provides another perspective on her actions:

*“... and then it's like when I talk to my colleagues,  
'The thing is, it's off, that's the good news  
You could have sent her away and said,  
it's nothing and you don't need to do anything about it.'”*

It is possible to consider this perspective has been offered to comfort or console Dr X, suggesting she think positively about what she did by comparing her actions to other alternative diagnostic choices available to her. Their counsel offers a unique insight into the diagnostic autonomy available to clinicians who can use their discretion to decide on their patient's behalf if further investigation is warranted. It is a position that Jutel and Nettleton (2011, p. 796) suggest has survived from the paternalism of days past:

*“Even in our contemporary era, where a greater emphasis is placed  
on the lay person to play a more active role, the diagnostician in  
the medical setting remains the key arbiter and thereby still holds  
significant jurisdictional authority.”*

However, it seems the guilt and questioning is not assuaged by the professional views of her colleagues. Dr X intensifies her efforts to get her patient appointments with specialists:

*“Then if it turns out to be something then that's a bad thing  
but it's this whole sense of how comfortable are you in this whole  
system.  
What's a reasonable amount of time?  
So I was sending off letters saying,*

*‘Please see this woman’ to the plastics department  
and feeling a bit panicky myself about it and thinking,  
‘Oh you know it fits in a criteria which could be nasty for her’  
and I am just wanting to expedite this whole thing.  
So I’m sending it off and sending off another one saying,  
‘I’ve got blood tests and I’ve got this and that.’”*

Dr X questions her comfort within the structured secondary care system she is dependent upon to provide the next stage of care for her patient. Now time becomes a critical feature of her narrative and having assessed the risk of losing time in earlier passages, Dr X seems to want to make-up time or at least ensure time does not further impact on her patient’s prognosis. She is both within the system, as a general practitioner in primary care and outside of this system, when her patient is referred to secondary care. There is a sense of a tacit negotiation with others that transpires in her communications, as her authority in this domain is diminished. The protocols of communication are evident in the politely addressed letters of request. She must bid, on behalf of her patient for the scarce resource of time in the system. Her experiences of this diagnosis process portray the analysis of diagnosis by Jutel and Nettleton (2011, p. 799) as a “means for casting light on the interplay between medical care providers and professional territories“.

Dr X’s narrative offers a markedly different experience of time than in Dr B’s account, where disclosure is scheduled in clinic time and offers him the opportunity to draw his patients into the immediacy and certainty of “therapeutic housekeeping” (Good 1994, p. 858). Like her patient, Dr X must wait, uncertain of when the results of the biopsy will come to her. This uncertain timing limits her power to influence, organise, or prepare for the disclosure to her patient. In this way, it is the times in between the consultation which impose on Dr X’s experiences more than Dr B’s (Jespersen and Jensen 2012).

In the medical hierarchy of knowledge, Dr X’s knowledge of her patient becomes subordinate to the opinions of other medical specialists, constraining what actions she can take other than to broker her patient’s fast-tracked appointments (Johansen et al. 2012). Her impression management is critical to the ongoing negotiation of trust in her relationship with this patient and as such, her narrative unfolds differently to Dr K’s, yet they engage in the same process of scheduling appointments and guiding their patients toward other medical specialisms.

Dr X returns to her ethical decision of when to disclose information to her patient, contrasting it with that of a colleague in her general practice:

*“I don’t know how they would deliver that news themselves  
but I know that they wouldn’t be thinking about it in the night or  
in the weekend*

*whether their decision to not tell somebody that weekend  
was the right or wrong thing to do.  
That they just make that decision they don't need to know that.  
I'm not there to say that's not right."*

The reintroduction of her colleague to this narrative provided another lens to view her experience against. Her decisions are weighed up against what she is certain her colleague would have done and it sets the scene for the uncertainty she experiences in her decision to tell her patient when she did. Her colleague by comparison is decisive and confident they are making the right decision on behalf of the patient. Dr X does not judge them for this, rather there is a sense she is contemplating this response as preferential to her own; it is their comfort with their decisions rather than the actual decision. They are not awake at night wrangling with the ethical dilemma that Dr X experiences in the same situation:

*"but to me I analyse all these sorts things,  
if I've got the information have I got the right to withhold it from  
someone  
who may well be waiting and want to know?  
And that's what was going on for me and this whole thing about  
this woman,  
now I know.  
I can sit with the discomfort of knowing except should I do that?  
Do I have the right to do that?"*

Dr X's analysis introduces differences between herself and her colleague. Her patient is central to this decision and she is aware of her power in their relationship. In this respect, Dr X's narrative is focused more on her patient's lifeworld than Drs K and B. The clinical facts are "not separated from the person who experienced them" but embedded in her patient's temporality (Johansen et al. 2012, p. 576). She is prepared to take on the discomfort of her decision to tell in the hope this will ease her patient's discomfort waiting for, and hearing, the diagnosis.

Dr X sets herself apart from her colleague because she questions the medical authority bestowed on her that allows her to withhold information until a more suitable time. Johansen et al. (2012, p. 576) suggests the continuity of a GP's relationship with their patients over a longer period of their lives can command a deeper loyalty and greater opportunity for a "shared humanness" (Johansen et al. 2012, p. 576). Dr X's medical practice is grounded in her respect and acknowledgement for her patients and her own lifeworld experiences.

The continuity of her relationship with her patients is a source of enjoyment and satisfaction and means she must also manage her “performance” over an extended period of time (Goffman 1959).

Clearly it would be easier for Dr X to make an appointment for her patient to disclose the diagnosis but unlike her colleague, Dr X determines in this instance it is unethical because asking her patient to wait over the weekend could intensify her anxiety.

*“And therefore I felt like I wanted to tell her  
and at least give her the option to come and speak to me that day  
but as it happened it didn’t go that way in the end.  
I feel though that in hindsight would I have been better to do  
what my colleague would have done and said:  
‘Well they don’t need to know this on a Friday’  
Maybe it would have been better to do it on another day.”*

Sitting with the discomfort of knowing evokes a sense that staying still will be no more comfortable than the action of telling her patient. Time becomes the catalyst for this dilemma.

## Conclusion

Understanding the role of the diagnosis process in the clinicians’ experiences of disclosure has emerged as a central feature in the often diffuse, complex and diverse stories of when, where, why, what and how clinicians are “telling bad news.” Disclosure of test results and treatment outcomes are present at each juncture in the diagnosis process mediating and sometimes distorting disclosure as a single moment and a protracted series of events.

All of the narratives portray a process that slices the diagnosis into steps and stages, at times alienating the clinician as it does the patient, both of whom are asked to wait ‘patiently’ for the final diagnosis. For Dr B’s patients, this diagnosis time can be extended for years, as patients commence a five-year outpatient’s programme, in a liminal state between treatment and cure, where the threat of recurrence of cancer hovers in the biannual encounters with his patients.

In Dr X’s narrative there are similar “temporal adjustments” thrust upon her as she negotiates the timing of diagnostic procedures and questions timing of the disclosure moment for her patient (Jutel and Nettleton 2011, p. 794). Similarly, as the clinician’s narratives outline a process where their patients must negotiate the “order of professional boundaries and organisational responses of formal care provisions” so to must the clinician (Jutel and Nettleton 2011, p. 796). Dr X’s narrative reveals the tensions she experiences



navigating a system of health care on behalf of her patient that has become “increasingly fragmented and specialised” (Jutel and Nettleton 2011, p. 796).

Routines of clinics, diagnosis and treatment provide certainty, predictability and back-stage preparation for clinicians’ disclosure performances (Goffman 1959). In Dr B’s narrative an early detection of breast cancer diagnosis was accompanied with an expectation of cure and survival. There was a greater sense of an ordered and more certain diagnostic and disclosure routine. For Dr X the timing of the diagnosis and the reading of diagnosis created uncertainty and an awareness of her experience of this as different to her colleagues. Uncertainty is not a feature of Dr K’s narrative of diagnosing cancer in his patient, yet blurred boundaries of truth-telling emerge in the trajectory of care that follows for his patient.

In their own unique ways, each clinician has in their sights the patient to whom they are disclosing the diagnosis. Yet in each narrative, the clinicians’ experiences of the diagnosis process and the disclosure moment(s) are remarkably different. Dr B’s narrative is without emotion while Dr X is kept awake at night worrying about how she has disclosed bad news to her patient. Dr K offers nothing of his emotional experience but gives an impassioned performance of his stand on telling patients at the earliest possible moment.

In each narrative the telling moments located each clinician’s identity along a spectrum of professional beliefs and ideologies. A picture begins to emerge from these three narratives of diagnosis of the broader social and cultural landscape in which they are situated. Death and dying are professionally managed on our behalf and as long as there is always something to be done, there is a moral imperative for clinicians to be doing and patients to be accepting.

The orderliness of death and dying in this system of care suggests certainty and confidence in how disclosure is performed and experienced by clinicians in secondary care. Only Dr X’s narrative offered a less routine and more uncertain experience. This raises questions of how much the clinician’s experiences and emotional management of the disclosure process is influenced and managed by their socialisation to the medical profession. In the following chapter I explore the significance of medical socialisation and the power of professional expectations on the clinicians’ judgement of when to tell, how to tell and what to feel.



## Chapter 7

# Emotions and Expectations

### Introduction

Dr V: “... *the fundamental truth is that it doesn’t matter if we cure cancer tomorrow because the person whose cancer is cured will at some later point in their life be struggling with the thing that can’t be cured...and the underlying issue is that we’re mortal. And no matter how good medicine or breakthroughs in science are, it’s not going to help us address the absolute - which is we at some point will need to contemplate our mortality and actually deal with it.*”

It is through the diagnostic processes outlined in Chapter 4 that the socio-cultural and professional dynamics of medicine surface in the clinicians’ accounts of their experiences disclosing a terminal diagnosis or prognosis to their patients. Clinicians are expected to perform in specific ways by patients and peers. In this way the presentation of a diagnosis to their patients can be considered from the perspective of Goffman’s (1959) metaphorical use of the dramaturgical and the performance of medical professional. To deliver the presentation with the authority required for the patient to believe the diagnosis is legitimate, there is little freedom to radically alter the performance. Without the clinical environment, the medical tools and the pre-performance of the waiting room, suspicions could be aroused about the profession. This can be exacerbated if the clinician’s language, mannerisms and appearance are inconsistent with expectations of the medical professional (Goffman 1959).

Clinicians strive to be open and honest with their patients while balancing the needs of their patient. Ensuring patients felt they still had a sense of control over their medical care and knew they were not being abandoned if their prognosis was terminal was cited as a priority by the clinicians interviewed. Alongside this is a belief there is always something more to offer their patients often underpinned by the clinicians’ commitment to do no harm to their patients. Frequently premised on prioritising their patients’ needs over their own this is strikingly evident in the clinicians’ expectations of manag-

ing and expressing their emotions in front of patients and their families/loved ones.

However as medical professionals they are subject to a system of medical care and a hierarchy that significantly impinges on how their interactions with their patients are performed. How “feeling rules” of the profession where self-reliance, stoicism and neutral affectation are valued is interpreted in different ways by the clinicians I interviewed (Kasket 2006a, p. 386 ). Dr K felt the expectation clinicians do not show emotions had definitely changed but had to be balanced with professionalism:

Dr K: “...you can't go and blubber over them like an idiot, you know, you're the professional, you have your professional role, but you can certainly be empathetic and show that it's affecting you and you know...Nurses, some of the nurses cry, some of the nurses go to funerals. I tend not to go to funerals.”

I had wondered if the more home-like environments of hospice care, built on the philosophy of holistic care, where patients are encouraged, and some would say, expected, to express a full range of emotions would facilitate a more equal confessional relationship between patients and clinicians. Interestingly, the more overt expression of sadness and connection to family through their presence at funerals is identified by Dr K as the domain of nurses, who it could be argued in Goffmanian terms are the supporting actors to Dr K's performance (Goffman 1959). His comment suggests nurses are afforded a wider range of emotional expression in the feeling rules and indeed may be expected to provide this level of emotional labour as further assurance in the liminal ritual of the good death championed by the hospice movement (Goffman 1959; Hochschild 2003; Blows et al. 2012; Boland 2013). In contrast to Dr K, Dr Z talked of having openly expressed his sadness with his patients:

Dr Z: “I have had a tear running down my face. I have to not feel bad about that, I feel that that's not inappropriate. I don't hide behind a desk, I've got out of my chair and hugged people when they're upset and I don't think that's inappropriate.”

Yet, Dr B's position more rigidly adhered to the professional “feeling rules” as he considered his patients did not expect or want to see his emotional reaction to their diagnosis and it may also affect his clinical judgement (Kasket 2006a, p. 387 ):

Dr B: “By the same token, if you become emotionally involved with the delivery of the information I'm not certain that is a useful thing from the patient's point of view...I think you have to remain pretty emotionally neutral to be maintaining efficiency as a good quality clinician.”

Clinicians are expected to maintain “affective neutrality” in their encounters with patients; a trait they are socialised to value and enact in their professional identity “as it is associated with power, knowledge, and being above the challenge” (Kasket 2006b, p. 143). Learning the “feeling rules” of the profession as suppressing their emotion in the belief they would otherwise be overly affected for the next patient is coined in the research by Kasket (2006a, p. 387) as *‘There’s Always the Next Patient’* rule.

Time management becomes critical to medical specialists with competing and multiple demands in their working day which can easily encroach into night and weekend calls. This often demands that “doctors contain the extent of personal interaction in favour of professional detachment, that patients are treated as ‘cases’ rather than people” (Lupton 2012, p. 120). Dr B describes how the pressure of clinic time affects and influences his emotion management with patients:

Dr B: *“The reality of clinics is that it’s busy. Its throughput; its bang, bang, bang and you dealt with that consultation and there’s another ten or twelve people to see. So I think you do get very adept at switching off and switching on.”*

Dr B’s ability to switch on and off, for the next patient, illustrates how he has adjusted his emotional management to the expectations of his profession and the structure of the clinic. There is a rationalisation of his own emotions as subordinate to the demand of his profession to meet the needs of patients for his unimpeded clear-sightedness. As Jespersen and Jensen (2012, p. 346) suggest, the consultation “becomes doable because it can push surplus problems elsewhere, and because it can limit itself to a smaller contribution in a larger course of events.” In the secondary care health system, Dr B is able to describe with greater certainty the time it would take for his patients to be diagnosed and treated. His experience of time is of a predictable time, a schedule and routine. He does not express concern with these timeframes. Time, though, is something that can bring comfort to clinicians’ emotional experience of the diagnosis process. For Dr B, time mediates the emotional impact of disclosing a life-limiting diagnosis. However, when diagnosis occurs quickly and is unexpectedly terminal, the short timeframes of diagnosis, and shortened lives of his patients, particularly young patients, exposes him to feeling affected. Whereas, longer timeframes in the diagnosis process exacerbate Dr X’s discomfort because she is already conscious of her patient’s experience leading to this diagnosis and feeling some responsibility, seeks to avert further harm to her patient, and to herself, by trying to expedite things.

In this chapter I present an analysis of narratives from the interviews with Drs K and X, Dr Z and Dr B to illustrate how their experiences of disclosure are influenced and informed by medical culture. In these narratives three key themes emerge. Firstly the influence of medical culture on each clinician’s ex-

perience and management of the emotions they feel in the disclosure processes with their patients is explored. Intertwined with this and strongly resonating with the research presented by McNamara (2004), is the belief there is always something more that can be offered to their patients. The ability to offer patients other options and maintain their focus on treatment draws on the literature on disclosure where awareness contexts are blurred with efforts by clinicians to “soften the blow” and also block potentially uncomfortable emotional responses; their own, their patients and their patients loved ones (Timmermans 2005, p. 152). Closely related to both themes is the expectations clinicians’ have of their patients accepting what they can offer within the medical model of treatment and care. These themes are enmeshed in the broader interpretations of Mishler’s application of the technical, rational “voice of medicine” illustrating the tensions and shifting flow of communication between the clinicians and their patients (Barry et al. 2001, p. 488).

The narrative analysis continues on from Dr B’s description of diagnosing patients with breast cancer in Chapter 4 where he goes on to describe his emotional response to the disclosure process. This is followed by excerpts from Drs K and X in response to my question of what it is like when there is nothing more that can be done for a patient and the implications of this on their expectations of themselves. In the final narrative Dr Z’s story of his experience with patients who chose not to accept the treatment he can offer is presented to illustrate the significant emotional impact of this decision on Dr Z when as a result he is left with nothing more he can do for his patients.

## Narrative 1: Dr B

### Approaching the emotion

In the next part of the narrative with Dr B he responds to my question about how he prepares for the clinical encounter where he is disclosing a diagnosis of breast cancer to his patient. He clarifies this in reference to patients who will be “newly diagnosed they’ve got disease which they’re not ultimately going to die of, so seeing people with whom there is intent to treat with curative intent.” His response is then structured around his emotional experiences of this type of encounter:

*“So this is something you’re dealing with on a weekly basis.*

*So what is my approach to that?*

*Well realistically, it’s probably pretty pragmatic*

*and I think it’s very uncommon for me*

*to be emotionally affected by the consultation.”*

Dr B situates the disclosure of a breast cancer diagnosis to his patient within his frequent exposure to the process and the expectation of curing them. He speaks now in the first person; providing an ownership and individuality to his approach and his response. He talks of how things really are, though he qualifies his description of pragmatic with less absolute terms of “probably” and “pretty”, and in the next line with “uncommon”. This alerts to the possibility of other approaches and experiences, suggesting he is not always emotionally unaffected.

Dr B returns in this passage to the curative intent scenario. He employs a hypothetical patient; the average lady of sixty years, who can likely be cured, as a contrast to the young mother, who will die. “But I think I could honestly say that my average, the average sixty year old lady coming in with a newly diagnosed breast cancer these days I would be emotionally neutral about it because you’re doing it every day.”

Dr B reasserts his response to these patient encounters as emotionally neutral. Here too, there is an interesting shift to the first person, “my average” that he corrects to “the average” in the second line. He repeats the attribution of his regular exposure to this type of clinical encounter and also the length of time he has been doing this, “these days,” to his emotional neutrality. His emotion management suggests a temporality from earlier days, perhaps as a medical student when he may not have been as adept at managing his feelings, to the present, “these days” where he is in control of his feelings and regularly exposed to disclosure situations. Socialised in overt and subtle ways over and over again, as medical students and junior doctors, to aspire to being “an affectively neutral technician” the “signature rule of the professional” is to never become personally or emotionally involved with patients (Kasket 2006a, p. 143).

Continuing the narrative, the rhetorical question is repeated. Dr B introduces the risk that his approach could negatively affect his patient by his experience of emotions in their encounter.

*“So my approach to that,  
and I don’t think you’d do the patient any favours  
by being emotionally labile during a consultation  
and I don’t think that’s what they want  
and I don’t think that’s what they expect.”*

Drawing on terminology borrowed from psychology, Dr B classifies emotions within a paradigm of abnormalities (McGann and Hutson 2011, p. 22). This is a feature of his narrative he also applies to his description of one patient’s ‘extreme’ reaction to a diagnosis of breast cancers as “pathologically abnormal”. Constructing extremes of emotional responses allows Dr B to propose an unthinkable and irrational way to behave in a professional context.

This duality of emotions from neutral and labile, however, effectively eliminates a myriad of emotions in between, some of which his patients may want expressed and some that may better sustain him (Lupton 2012). As such, it seems that he is denied the experience for risk that it will leak into the performance of being a professional clinician. Studies have found that clinicians have a fear of losing control of their behaviour and their patients reactions when disclosing bad news (Friedrichsen and Milberg 2006). Dr B's very genuine concern that he could cause some harm to his patients were that to happen is echoed in the research, suggesting suppressing emotions, rather than contaminating the clinical encounter with this unprofessional display, is a common way of coping.

Struck by his unexpectedly candid response, my response prompts Dr B to define an exceptional circumstance where he may be affected:

*“Jo: Is it?”*

*Yes. With the odd exception of, for example, that one we we're talking about;*

*that woman who was one week post-partum*

*with a three year old,*

*a one weeker*

*and a husband,*

*who was almost certainly*

*going to be dead*

*within twelve to twenty-four months.*

*It's pretty difficult not to be affected by that.”*

Dr B references a patient he had described earlier as an example of the extreme end of the spectrum of patients in his care. She is unexpectedly diagnosed with metastatic breast cancer after experiencing some back pain while in hospital following the birth of her second child. A dualism of emotions emerges; his emotionally unaffected response to seeing a patient with intent to cure, and feeling affected when he has to disclose imminent death. In contrast to the first section, Dr B does not use the first person, contributing to a less personalised account. He has a central role in this disclosure also, but his ownership is less noticeable than in other parts. Without the background information it could only be assumed that this is his patient who he has diagnosed with terminal cancer and he is directly affected by this.

Stenmarker et al. (2010, p. 482), in their research on paediatric oncologists breaking bad news, talks of how life-threatening conditions and death in children “contradict the order of nature” and these difficult circumstances often result in a continual grieving process for health professionals. Though,



for Dr B, “happily this is not a common scenario.” He references it three times in the interview, amplifying the significance this scenario had for him. They suggest, that although the “existential provocation remains unresolved,” clinicians managed by having a “carefully prepared view” of their central life issues to risk “transmitting” their own fear of death to the patient (Stenmarker et al. 2010, p. 481). Dr B employs clinical language with casual intent to describe and possibly distance himself from this experience, though there is also a sense of heightened drama of the intensity of this situation, as if his emotional affectation must be explained by a justifiable cause.

The emotional labour demanded in medicine is offered without formal external supervision, rather as Kasket (2006b, p. 139) suggests in her research, clinicians engage in their own “emotional supervision” where an “awareness of professional norms and of expectations from all sides might certainly make a physician feel that emotional faux pas will be noticed and disapproved by someone”.

Interpreting the norms of the medical profession is likely to also include the stigma of mental illness which infuses Dr B’s categorisation of emotions as “neutral” and “in control” or “labile”. Later in the interview I asked Dr B if colleagues shared with him how they felt in difficult situations and his response reflects the “conspiracy of silence” Wallace (2010, pp. 7–8) refers to in her research:

Dr B: *“Not with respect to psychological aspects of dealing with the patients, it’s more with respect to a difficult management problem, like patient’s got a complication and how do they deal with it or they know a patients coming up with a particular surgical problem and so it’s not feeling really upset because Mrs Robinson’s got a recurrence of cancer.”*”

Testament to the hallmark of a “culture of invulnerability”, it is the fear of making a technical mistake in the management of a patient more than the experiences of disclosing a life-limiting or terminal diagnosis to their patients that is considered a greater concern (Shaw, Brown, and Dunn 2013, p. 246). This in part he explains as a result of the fear of reprisal from another audience:

Dr B: *“Under-riding that is there is always a background fear, not so much litigation in New Zealand, as HDC and complaints process and things like that. I think that’s what generates angst for practitioners not pouring their heart about the patient has a got a bad disease process which is nothing to do with how they’ve managed the patient and nothing to do with their ability to deal with the natural history of the disease.”*

The extent of doctors policing one another is apparent in this response from Dr B and is exacerbated by the introduction of a higher authority with

the power to publically bring to light any failed performances (Charon 2001). It is not surprising then to find Dr B acts relatively independent and alone with regard to the less medical aspects of his work (Grönlund, Dahlqvist, and Söderberg 2011).

As a surgeon, Dr B must act with clarity, focus and precision. He must be certain of his performance and cannot afford to lose control not only because of the physical risks inherent for his patient but he also when he is in front of an audience ‘performing surgery’. While the team support his performance, they may also see if he falters. Managing his performance is an ongoing effort to reinforce his status and professionalism as a surgeon. As Goffman (1959, p. 40) suggests:

*“... performers often foster the impression that they had ideal motives for acquiring the role in which they are now performing, that they have ideal qualifications for the role, and that it was not necessary for them to suffer any indignities, insults, and humiliations, or to make any tacitly understood ‘deals’, in order to acquire the role...in part to foster the impression that the licensed practitioner is someone who has been reconstituted by his learning experience and is now set apart from other men.”*

I asked Dr B whether there were any specific things he consciously did when shifting from work to home. Unlike Dr X in Chapter 4 he was not kept awake at night worrying about how he has responded to his patients:

Dr B: *“I don’t think so specifically with respect to dealing with the breast cancer patients for example. If you’ve seen a particular bad, somebody is in a particularly bad predicament with respect to their disease I think you’ll think about that but it’s ... I don’t lose any sleep about it, you’ll feel I don’t know if upset is the right word necessarily because that it’s almost like you’re taking a stronger personal emotional attachment, I think you’re ... I hate to think that you would lose the ability to feel the person and where they’re at but I think that’s different than being significantly emotionally upset.”*

Dr B’s approach to the disclosure of a breast cancer diagnosis to his patients in Chapter 4 and the emotion he experiences is evident of his own emotional policing suggesting if he feels upset he has digressed the rules of attachment to a patient. He is committed to the patient and their needs, seeking to maintain his connection with where they are at but again returns to the feeling rules to determine this is acceptable only when it is compared with the more extreme response of “being significantly upset”.

As a surgeon, Dr B is generally positioned to be able to soften the blow of a breast cancer diagnosis by offering a range of treatment options and in

doing so, manage the emotional intensity for himself and his patients. Mostly there is always something more he can do and in the following narratives from Drs K and X, the significance of these offerings to patients and their families is apparent in their emotional responses and expectations of themselves as caring physicians.

## Narrative 2: Dr K and Dr X

Dr K champions palliative care, repeating his mantra “palliative care is active care” to junior doctors and senior colleagues alike. Unlike some of his medical colleagues, Dr K does not believe there is ever a time to stop diagnosing and treating a person who is dying. There is always something more that can be done for a patient and he always has “plan a, plan b, plan c” formulated to communicate to his patients, their families and loved ones and his fellow practitioners. He acknowledges “dying is inherently uncertain” with an “inherent lack of control” but works hard to anticipate and plan for what could happen.

### There’s Always Something More That Can Be Done

I was surprised that there was always something more that could be done, anticipating and assuming the hospice ideal of a good death was a quiet, peaceful and natural retreat into death, without medical interventions. I had also thought there would be situations where nothing further could be done to stave off death and medical interventions would be inappropriate in the final terminal phase. With this in mind I wondered if there were situations where Dr K’s confidence in his mantra may not always ring true:

*“Dr K: . . . the other phrase I can’t bear to hear is: ”There’s nothing more we can do” because in my book there is always something more we can do, always.*

*Jo: Are there times when there is nothing more that can be done?*

*Dr K: No.*

*Jo: Never?*

*Dr K: Never.*

*Jo: There’s never been a time when someone’s pain can’t be controlled?*

*Dr K: You can increase the medication, you have to talk about the side effects from increasing that medication ...your goal of care is that relief of symptoms but it’s an infrequent thing.”*

For Dr K to think, act or say “there was nothing more that could be done” was “tantamount to euthanasia.” He defended the use of palliative

sedation, outlining the rigorous consent process and rarity with which it was administered. Without prompting in the interview Dr K raised euthanasia many times, particularly with reference to it being “an act of killing, not an act of medicine.” Dr K talked of the ways he and his team care for dying patients in a holistic hospice environment where spiritual, physical and emotional care are accorded equal prominence. Much of this is centred on “reframing hope” for his patients as each loss chipped away at their sense of hope:

Dr K: “... *the young mother who died last Sunday, who’s two daughters were here today, she wanted to get home for a period of time. She knew she only had a couple of weeks. She was upset. They hoped they could bring Christmas forward so she could have Christmas with her kids. Well that happened. She was home thirty-six hours and they had Christmas. That was her hope. So it’s reframing the hope.*”

His response echoes that of Dr X who shared the view there was always something that could be done for a patient expanding more fully on what that might be:

*“I think actually to say to somebody, ‘There’s nothing more that we can do’ - I don’t think that everybody would be in a position to break that kind of news because most of the time there is something you can do and so part of it is how you frame that.*

*Like if there’s nothing more we can do,  
does that mean to cure you?*

*Or does that mean to help you have the most satisfying life that you have the potential to have?*

*And what does that mean to you?*

*Does that mean having some sort of therapy that prolongs your life because that’s the thing that you want to have?*

*Or is it choosing that you want to have certain types of pain relief?*

*Or you’d like to go travelling and is that a good thing to do?*

*In some ways it feels to me like there’s always something you can do*

*and part of what I feel about it is that there’s a responsibility,  
I’m not sure if that’s the right word,*

*I have the sense that instilling hope in people is a really core thing of my values,*

*for people to have a sense of hope.*

*Not necessarily a sense of hope that they’re going to be cured.”*

Both clinicians' narratives portray the restoration and maintenance of a sense of hope for their patients and their loved ones. Dr X explicitly connects this to her "core values" suggesting this has been a driving motivation for her call to the profession. Dr K also talked about being attracted to the profession because he can help people. To some extent both have responded to the social and cultural expectations of medicine as a helping profession and their expectations of what they can offer their patients when a medical cure is no longer an option extends to a broader interpretation of what that might mean. Integral to instilling hope is always being able to offer something to their patients even as physical illness and dying diminish not only what the patient can expect to do but what medicine is able to offer. The gambit of doing extends to beyond the realm of medicine to include offerings previously unavailable in the biomedical model, such as art and music therapy, spiritual counselling, palliative treatment and supporting families at home. In this respect there is an "absorption" of what Timmermans (2005, p. 1000) describes as potentially competing therapies into the control of the medical management of death and dying.

However, this brings to question if always having something to offer patients is not only more easily achieved with technological advances in medical care and the holistic approach to hospice care but as Field (1996) suggests also provides the clinician with a way to mediate their disclosure conversations with patients. Focusing on the next course of action, even if this is delivered by another specialist or therapist continues to engage patients and their loved ones in a medically framed future (Good 1994). It could also be argued the process of engaging in hope restoration is restorative for the clinician also as they face their patients' physical and for many, existential suffering.

In contrast to the narratives of hope above, Dr Z offers a story from one of a series of situations that he found distressing. In each of these situations his patients had responded to his diagnosis and treatment with some form of resistance, from denial of the prognosis he offered to rejection of biomedical treatment. He referred to these situations as "sub-types" he found distressing because; "I haven't been able to care for them or get across where they are in all this and how I can contribute to some extra life and above all their quality of life." The distress he experiences is counter to the gratitude and joy he feels in most of the clinical encounters with his patients and their families. Dr Z spoke with a modest pride of his ability to communicate bad news to patients and most of the time be successful in "bringing them around" toward an acceptance of his gifts.

Dr Z: *"I think I'm quite good at doing it; most times I can do it so that it's a positive experience for the patient and the family. And it's often; if you've said to them that they've got a few months left that you get a hug from everybody on the way out."*

He describes this type of reciprocity as the “gifts” of gratitude he gets every day from his patients that counter the cumulative battering from dealing with “the numbers of people you would have seen and the numbers who did actually die and the number of conversations that you had around, “Look I’m sorry, do you want to know where you are in terms of life expectancy?”’

### Narrative 3: Dr Z

When I arrived for the interview with Dr Z, a radiation oncologist in private practice, I wondered if I was in the right place. Walking to reception I passed an empty waiting area, soft lighting and intermittent birdsong guided me to a caring receptionist. Unlike my experiences waiting in public hospitals, I felt immediately important and cared for. The contrast to public hospital environments disturbed by jarring bangs, crashes, harsh lighting and beaten-up furniture was striking. Dr Z immediately appears, greets me and we go to his office. Although the room is furnished with a couch, he sits at his desk and I select from the line-up of chairs adjacent to him.

Initially it is hard to read his demeanour, he offers little of the warm and engaging professional which emerges as the conversation flows and I wonder if this is part of his technique. His calm yet aloof approach begins by asking me to tell him what I have learned so far in my research. As a senior clinician, Dr Z speaks with a sense of confidence in the wisdom and insights he offers from his vast experience. Quietly spoken, and at times almost inaudible, I am physically and mentally drawn in closer. I am closely attentive to his words and more intimately engaged. In this story, Dr Z talks about a group of patients who reject the biomedical model and seek alternative treatment which again, contribute to his cumulative feelings of grief and failure.

### Die When They Could Not Have

*“Another group of patients that you don’t come across that often  
but can be very distressing are those few patients  
who totally abandon your advice around orthodox medicine  
and go for alternative medicine.  
Now I have a fairly generous view about complementary therapies  
compared with some of my colleagues, I just say,  
”Actually you can spend a thousand bucks at the health food shop  
but you’d be better off buying a pair of running shoes and walking  
in them  
because that degree of exercise is going to help with your immune  
fighting*

*and there's evidence to back that up."*

*"No I don't think you should go to a clinic in Mexico."*

*Bolivia is now the fashionable place.*

*There are sadly quite a lot of doctors who end up being quite fringe, often general practitioners who see some sort of vibrant light and say,*

*"Well I can do this, this and this."*

*Once that gets in the way of a choice that could actually truly make a difference*

*that is very difficult as a clinician who cares.*

*And they die when they could have not died.*

*You can't guarantee you would have cured them with the orthodox medicine*

*but you would have had a lot greater chance than what they took."*

Dr Z opens with positioning the patients he is describing as a group that he does not see often, though this does not mitigate the distress he experiences. The immediate orientation to his patients' behaviour as irrational is apparent and it is interesting Dr Z describes this as abandonment. In light of his sense of rejection and failure as a result of these types of distressing situations, the sense of abandonment suggests it is more personal than his patient's rejection of biomedical, orthodox medicine.

In this story Dr Z's patients are not directly recognised as health consumers who may have carefully and methodically investigated the medical interventions available to them. The social and cultural scripts in Dr Z's medical management of patients with life-limiting diseases appear to exclude their lifeworld beyond that which is considered medically amenable to interventions. In the fight against time against death, patients are expected to accommodate the imposition of medical interventions with all the attendant additional suffering in return for more life. Dr Z's response to his patients' choices mirror the literature on compliance and concordance, in particular, as Conrad (1985) suggests, not all people share their doctor's view and may choose to respond in "non-medical ways" that can seem "an illogical form of noncompliance" (Conrad in Brown, 1995, p. 45).

There is the presentation of a dualism between alternative medicines as 'unorthodox' and subordinate to the orthodox medicine Dr Z can offer which can cure patients. This dualism positions medicine with life-giving and extending powers in the battle with death and more 'natural' therapies as an alternative not only to orthodox medicine, but in these circumstances, to life. Dr Z's patient is again, non-compliant in refusing to accept the medical interventions he offered and in this story, their beliefs and those of some of his

medical colleagues is called to question. Describing some doctors, predominately GPs as “quite fringe” is illustrative of Dew (2000, p. 1792) research on medical acupuncturists who are seen as deviant, possibly even fraudulent and market-orientated. He suggests the use of alternative therapies by medical practitioners creates an “uneasy tension”:

*“For the medical profession, the problem of the use of alternative medicine by medical practitioners has not gone away. The medical profession has struggled for decades to come to some form or rapprochement with its members who are attracted to alternative medicine. This uneasy tension between the profession and its members has to some extent been settled today, with the New Zealand Medical Council gaining powers through the Medical Practitioners Act 1995 to assess practitioners and oversee quality assurance procedures. In addition, guidelines have been developed for all practitioners who use alternative medicine to indicate where they step over the boundary and defy the social norms of their community (Dew 2000, p. 1792).”*

This tension can be read in Dr Z’s story where alternative medicines are acceptable as complementary to orthodox medicine only, and tolerated until they do become alternatives and “get in the way of a choice that could actually truly make a difference.” His belief in the power of medicine to make those choices suggests a more paternalistic approach because he has defined for himself what would make a difference for his patient and is distressed when his patient does not share his view. The encroachment of alternative therapies into the clinical encounter, renders Dr Z bereft of gifts. There is nothing more he can do and his performance is not just disrupted but abruptly ended.

Dr Z’s experiences of his patients as active health consumers were echoed by Dr B. Although he experiences most of his patients as “pragmatic and rational” and people who “listen to what you’ve got to say and make an informed decision”, he describes with some frustration, the two or three patients he sees each year who contest his advice and based on “misconceptions” request more extensive treatment:

*Dr B: “One of the issues I find is when people come in from the get go... with very fixed ideas and it’s not necessarily from trolling over the internet or whatever; it’s often from the girl next door in the neighbourhood or Auntie Madge or whatever had breast cancer and she had this done.”*

He realises some patients will have a better outcome psychologically when the treatment they request is more extensive than required, for example, a full mastectomy even if it is not medically necessary, although considers it does



not change the effectiveness of the treatment and their long-term outcome. Dr B does not describe the same sense of failure with these patients; rather he seems to express a more forceful response:

Dr B: *“It’s trying to deal with those people, as a more common scenario, or albeit happily not that frequent, but trying to knock down preconceived misconceptions. The people who come along with the raft of information from the internet are normally of a personality type whereby they’re going to be hard work anyway they’re a certain type of person.”*

Like Dr Z, Dr B appears to group these patients into a type, in a way that appears to section them off from his more frequent experience with patients. Referring to the group as a personality type seems to distance the opportunity for feeling he has personally failed. Unlike Dr Z who is left with nothing more he can do when his patients choose to seek alternative treatments, Dr B remains actively involved in his patients’ medical journey and is able to accommodate their choice in the orthodox biomedical management of their disease.

## Conclusion

Attracted to the medical profession to be able to help their patients and armed with the medical arsenal of offerings which has extended beyond sophisticated pain management to spiritual and emotional guidance, the clinicians act to restore hope, dignity and control to their patients. However when patients act to control their dying in ways that are outside of the expected response to this model of care and treatment, clinicians can be left bereft of further involvement.

The power of their socialisation to the medical profession is apparent in the narratives presented in this chapter. Emotional responses to patients are regulated by both an overriding desire to protect the patient from any additional suffering the clinicians’ emotions may engender and professional policing of appropriate emotion management.

Overarching this analysis is the organisation and structure of medical care dominating, interrupting and also mediating the clinicians’ relationships with their patients and their colleagues. Time with patients is managed and controlled through the structure of medical care. Fractured into clinics, surgeries, diagnostics, and referrals to other specialists, medical time dominates and can subsume the patient’s lifeworld while routinising the disclosure experience for clinicians.

The narratives bring to the fore questions about how always having something else to offer patients affect the clinician’s experience of disclosure and if there is always something more that can be done for their patient, does it

also assume the patient should always want something more to be done? This leads to how disclosure experiences for clinicians are more than moments of telling, in the context of open awareness and health consumerism, requiring the clinician to negotiate or “broker” their patients’ entry to the trajectory of medical treatment and care to follow (Timmermans 2005, p. 993). Positioning disclosure in this way facilitates an analysis of the clinicians’ experience of failed performances or negotiations which follows in the next chapter.

## Chapter 8

# Failure and Demoralisation

### Introduction

*“Despite all our grand societies, our memberships, fellowships, specialty colleges, each with its own annual dues and certificates and ceremonials, we are horribly alone. The doctor’s world is one where our own feelings particularly those of pain and hurt- are not easily expressed, even though our patients are encouraged to express them. We trust our colleagues, we show propriety and reciprocity, we have the scientific knowledge, we learn empathy, but we rarely expose our own emotions (Verghese in Frank 2004, p. 4).”*

Disclosing a terminal diagnosis or prognosis is not always a clear-cut and distinctly defined act. The experiences from Chapter 4 support the argument that telling is often within a process of treatment, testing and further diagnosis. At times there is a sense of the ordinary and routine when patients and their loved ones progress through a defined trajectory of medical care, falling neatly within the specialisms of primary and secondary medical care and often exiting with a successful outcome, be that survival or a good death.

Permeating these experiences are the powerful discourses of medical culture identified in Chapter 5; influencing and determining professionally and socially acceptable responses from clinicians and patients alike to the disclosure of a terminal diagnosis or prognosis. However if disclosure is a routine process why does it continue to be widely debated in the literature and the subject of so many models of patient-doctor communication?

Challenged by the more routine diagnostic response and with the sense it was more than just telling a diagnosis in the disclosure experiences I was hearing, I probed for situations beyond the routine, the generalised, the controlled and manageable to get answers to my questions. I wanted to know if there were times when disclosing a life-limiting diagnosis to their patients was more difficult, than others, and if so, why. If the diagnosis was the “front-stage” presentation of self, I wanted to know what the consequences were, if

any, for clinicians when the “orderly social interaction becomes disorganised” and what social and cultural scripts they drew on to navigate in uncharted trajectories (Goffman 1959, p. 214).

In this chapter I explore the clinicians’ narratives that recall times when the disclosure of a terminal diagnosis or prognosis has been difficult, and as such, less routine for the clinician. These stories are presented because they provide poignant glimpses “backstage” into the extraordinary experiences medical professionals face in the context of what have become ordinary expectations of the profession and society more broadly. The impact of these expectations I argue is rarely considered from within or outside of the profession (Goffman 1959, p. 214). Building on the themes from Chapter 5, each narrative illustrates specific pressures on the clinicians in the process of telling or “brokering” their patients’ ritualistic passage toward the medicalised trajectory of treatment and care (Timmermans 2005; Maynard 2003; Blows et al. 2012, p. 993).

Most noticeable is the patient’s voice; directly or indirectly through their physical body; it is comparatively more present in these stories. The generalities of diagnosis and disclosure previously discussed are less hypothetical and in the presence of a patient and the voices from their lifeworld, fraught with uncertainties. What emerged as a result were experiences that spoke of frustration, distress, and failure for the clinicians and seem to interject and at times silence, their voice of medicine (Barry et al. 2001).

It is within these narratives infused with a sense of failure and the potential for demoralisation where I contend the imperative for change lies. I question why clinicians who bear witness to so much suffering are so frequently unsupported when in our society it is now acceptable for the archetypal masculine hero, a former All Black, to publically champion mental health awareness from his own experiences with depression.

I begin with a narrative from Dr B. Face-to-face with a non-curative diagnosis, Dr B is unexpectedly caught without time to prepare himself or his patient for the outcome. Unlike the linear progression of the diagnosis narratives in Chapter 4, the immediacy of this diagnosis and disclosure is pronounced. Correspondingly his narrative illustrates how expectations of treating with “curative intent” and the structure of clinical work distance him from the emotional effects of disclosure situations.

This is followed by Dr Z’s narrative, another story from a series of disclosure experiences and encounters with dying patients who are not wholly complicit with the biomedical management of death. Patients are heard in his narratives as health consumers exercising their right to decide on how their illness trajectory will be managed. As such, the tension of brokering his patients’ acceptance of orthodox treatment while respecting their rights to manage their adjustment to their illness with integrity is striking.

In the final narrative of this chapter, the theme of always having something more to do in the medicalised control of dying in Chapter 5 follows through

in a story from Dr K. His relationship with dying patients in palliative care is a negotiation with time and hope. Prognosis is infused with always having a plan to address the inherent uncertainties of death. In this narrative, Dr K retells the experience of trying to control and manage his patient's unexpected seizures with her loved ones at her bedside. He is caught in a situation he is unable to control, denying him the opportunity to facilitate the ultimate 'good and peaceful death.' Unlike Dr K's first narrative of the classic patient diagnosis in Chapter 4, and his vehement commitment to always being able to offer something to his patient, here he is left questioning what more he could have done.

Rather poignantly in each story there is a resistance from the patient. Although unintended in Dr B and Dr Ks' stories, where the patients' physical bodies determine the success of their medical actions, the result is the same as Dr Z's patient who cannot be brought round to accepting the care he can offer. There is an overwhelming sense of powerlessness and a deeply embedded sense of failing their patient. To conclude, drawing on Frank's (2004, p. 86) work I look at the risk of "demoralisation" for clinicians when the cumulative experiences of failure and ongoing pressure to respond with stoicism is considered. With the risk of demoralisation present, questions arise of what might be done differently to better support clinicians. These questions inform the analysis of alternative narratives explored in the final chapter (Frank 2004, p. 137).

## Narrative 1: Dr B

### The Christmas Patient

In this narrative, Dr B shares his experience disclosing a terminal diagnosis to his patient. She is presented by Dr B as a close fit to the profile of his "average" patient described in Chapter 4. In her mid-sixties and following seemingly successful operative and radiation treatment five years earlier, his patient was coming to the end of the follow-up programme. Attending a consultation with Dr B prior to Christmas, she appeared "entirely asymptomatic", but as part of his routine examination he detected some suspicious hard feeling lymph nodes in her neck. He ordered a needle test and scan which showed his patient had metastatic disease related to the previous breast cancer. "She had disease everywhere, brain, lungs, bones, liver." Dr B described the extent of her disease as a very unusual scenario which was "clearly incurable."

In the following narrative Dr B continues on from a previous diagnostic description of the tests that he ordered, the confirmation of the disease progression and the list of palliative considerations for further treatment he had to talk with his patient about. He rounds this off with a return to the same rhetorical questioning which is a feature in the story of diagnosis:

*“So, question of how do you approach that?  
 Well I think that from my point of view it’s certainly more affecting  
 than the person you’re seeing for the first time.  
 This is a lady I’d known for five years been seeing her,  
 operated on her and seeing her probably a couple of times a year  
 for five years,  
 she walked into the room looking her normal happy, bubbly, self,  
 entirely well,  
 no symptoms  
 and ten days later we’re seeing her with the results of her CT  
 which shows she’s got disease she’s going to die of.  
 I think that is... definitely...you...it affects you unquestionably  
 but the reality is that,  
 what I’d like to hope I’d do is  
 interact with that person in a compassionate way  
 and not like a cold fish”*

For Dr B, his patient’s recovery seemed to be moving toward greater certainty as she neared the end of the five year programme. He described his patient affectionately from the connection formed over many encounters. She was “her usual bright, bubbly self,” suggesting an effervescence of life masking his ability to immediately read the symptoms of a recurrence in the physical text she presented to him. With the statistical likelihood of survival increasing each year following the initial treatment each consultation over this time probably increased the reaffirmation of trust in their relationship. In many ways his narrative is an example of the interpretative assumptions Leder warns of in the clinical encounter:

*“Almost from the moment the patient walks in, the physician is generating provisional diagnoses which determine which questions will be asked, what tests ordered. The physician must beware of conceptual inflexibility: the text engages its reader in dialogue and may at any moment explode one’s pre-existing interpretations (Leder 1990, p. 16–17).”*

While Dr B enjoys the opportunity to get to know his patients better over the longer period of regular follow-up consultations, and likens it to a GP relationship, he has also experienced the failure of the diagnostic processes. Furthermore, the follow-up programme positions Dr B to offer reassurance

he knows could be undermined by an undetected recurrence. Dr B had spoken earlier of how unreliable the physical examination can be because small tumours were hard to detect and many women presented without any symptoms. When symptoms were present and tumours were detected by physical examination, there was a less optimistic prognosis. Dr B describes this model of care as “lacking scientific evidence” and understandably there is a sense of failure and frustration when a recurrence is diagnosed in this context. In this respect, Dr B is continually renegotiating his patient’s trust in continuing with a breast screening programme when he can never offer certainty of their survival (Schaepe 2011). If Dr B is unable to accurately detect recurrences and is unable to treat with curative intent, his performance of disclosure is threatened and may fail.

Unlike his diagnosis narratives in Chapter 4, where the disease was referred to as independent of the women’s bodies it inhabits, here Dr B talked of the disease, as belonging to his patient; “she’s got disease she’s going to die of.” This type of disruption is one that Goffman (1959, p. 214) suggests may have consequences “from the point of view of the social structure”. His reputation, and the reputation of the efficacy of scientific medicine in the fight against disease, may be weakened. Dr B’s patient represents a potential disruption to this faith in medicine. Her terminal diagnosis is reflected as contingent to an individual incident (Callahan 2009). This is an example of what Goffman (1959, p. 31) describes as the socialization of a performance where the performance represents an “idealized view of the situation”.

Dr B reflected on what his emotional reaction to this situation was and as in his earlier narratives, moved to offer an explanation as if to justify the emotions he is experiencing before concluding with how he would act. His use of the word “approach” again refers to his emotional approach in both narratives, rather than what he would specifically do or say. Similarly, he referred to an affecting emotion from “his point of view” which provided a sense of ownership of the feelings he was experiencing. Emphasising his feelings of being affected “unquestionably” reinforces the sense his response must be defensible and without question as a medical professional. The emotional supervision occurring in this situation suggests an ongoing internalising of what is considered professional appropriate as “a product of the ‘latent curriculum’ of medical school, which continues on into the workplace” (Kasket 2006b, p. 146).

Referring to his experience I wondered how Dr B prepared for this encounter. In his response which follows the impact of the extent of the disease that seems to have progressed rapidly is apparent. Bereft of the lengthier diagnostic processes of his clinical routine in the first chapter and let down by regular diagnostic screenings over the course of the follow-up programme, Dr B is exposed to a clinical encounter with his patient that affects him emotionally. His emotional neutrality and generally unaffected demeanour is threatened by this sudden terminal diagnosis of a patient he has developed a longer relation-

ship with.

*“Jo: Using that example, before you see the patient you face your day and you know ”Ok I’ve got that? Is that right?*

*Dr B: Well that lady she came back from her CT  
and I literally saw her CT result  
about a minute before I walked into the room*

*Jo: To see her?*

*Dr B: Yes, because she came back,  
I knew she was back with the results of her CT scan,  
flip up her CT scan and was like  
‘Fuck, I can’t believe how advanced it is’*

*Jo: So you literally had a minute or two to prepare?*

*Dr B: Now sometimes you would have seen,  
because a copy of the report would come through into my in-tray  
but I think that one we got it all done fairly quickly  
so I don’t think I’d seen her report when . . .  
but quite commonly might have seen the result come through to you  
a couple of days before the consultation,  
on that occasion I hadn’t,  
but either way in that particular situation . . .*

*and there’s some cases where you know they’re going to have a bad  
scans  
just because of the way they’re presenting,  
the way they look,  
symptoms and things like that.*

*Whereas that was in the context of  
yes she had some obvious nodes in her neck  
but she looked entirely well,  
had zero symptoms whatsoever,  
she had not noticed these nodes  
it was just a chance finding by me at the clinic.*

*She went away and had this scan,  
it was sort of dotting the i’s and crossing the t’s exercise  
and the scan comes back showing she is riddled basically and  
that was, sort of blew . . . ”*



Dr B returned to the timing of this diagnosis, perhaps interpreting my question as a suggestion of some negligence on his behalf. His narrative began to resonate with Dr X's diagnosis narrative in Chapter 4 because the immediacy of telling his patient was now central to the narrative. However, Dr B was not faced with the uncertainty of when to tell his patient; the speed with which the scan was conducted and the structure of his clinics determined that for him. Unlike Dr X who was never certain when she will receive the diagnosis, Dr B talks of the ways he would normally have been prepared for the diagnosis of a cancer recurrence. The system of communicating a diagnosis between medical practitioners meant it might ordinarily have been delivered internally to his in-tray. Knowing this information for a couple of days before the meeting with his patient would have provided some time for him to prepare and adjust emotionally to the news.

On the surface it appears the crucial incident is the diagnosis leading up to telling his patient but in context it has a different interpretation. It is the surprise, as if science, statistics and her display of no symptoms had let him down as a reliable source of information and he is now caught off guard in what was supposed to be a routine consultation. The narrative peak is not what might be expected, that the woman is told she is dying, but rather it is Dr B's reaction to the results of the diagnosis.

It has been suggested that for patients the uncertainty generated by the possibility of a recurrence of cancer in the future "means individuals are effectively trapped between two social states: health and illness" that is likened to a state of liminality persisting for the rest of their lives (Blows et al. 2012). Dr B's experience of this liminality is also marked with the uncertainty of this recurrence. His role as "master of ceremonies" in the ritual is curtailed by the structure of medical specialities. He can only preside over his patient's survival at the end of the five year period, not their dying which is passed onto another specialist (Boland 2013).

Paradoxically, Dr B's skill as a diagnostician and through examination, "dotting his i's and crossing his t's" meant he had to tell this bright and bubbly patient, at a traditionally happy time of the year, she is dying. In the story Dr B tells, he seems unable to bring his narrative to a resolution, and fades away on his last words, "it sort of blew..." This is possibly to infer it "blew him away" as the 'exploding' of his pre-existing interpretation (Leder 1990, pp. 16–17). There is a sense he cannot easily reconcile how this terrible outcome has occurred during his watchful and extended diagnostic process over the past five years. His story also supports how time 'backstage' is critical to how clinicians can prepare for, and recover from, the disclosure performance (Goffman 1959). I wonder what might this mean for his registrars who are "cherry-picking" from how he is with his patients as they are socialised into the surgical profession?

In the second narrative, Dr Z's experience of disclosure is not disrupted by unexpected results he has to communicate, rather it is his patients' responses

to the diagnosis and treatment he offers. When Dr Z's patients resist, he is unable to guide them to the liminality of the dying ritual. It is as if they have taken back their diseased bodies and refused the gifts Dr Z has offered. Their refusal is experienced as rejection and failure by Dr Z.

## Narrative 2: Dr Z

The sub-types of distressing situations Dr Z described fractured his sense of reciprocity when patients did not share his views on accepting the diagnosis, progressing with treatment and extending life where they can. In the following story, Dr Z describes another of the sub-types of clinical encounters he finds distressing and the effect of this on his assessment of how well he has performed.

### Denial and Anger

*"Occasionally, it doesn't happen that often but occasionally  
you will have a patient who just actually does not want to know  
and it's often men.  
His way of coping is to absolutely deny that he's going to die  
and then you, me; I'm painted almost as the enemy.  
They don't come along that often, but they take a toll.  
Another one I remember like that was a man,  
is a very well-known name, what a great guy he was, and he was,  
but he had melanoma presented with secondary disease.  
Three days before he died he berated me  
for telling him that I thought he was in the last few days of his life  
and shouldn't his sister who lives offshore to come and see him.  
Seventy-two hours later he was dead.  
So that's what I told him, but he was so angry with me.  
That was really hard.  
Now in fact to be fair, this is a good example  
because it's probably now fifteen to twenty years ago.  
I occasionally see his widow around town  
and she gives me a hug and basically said,  
"It was just as hard for you as it was for me."*

*So he set her up for grieving for a decade before she could get her life together*

*and that is really hard. Sort of two percent as hard for me as it was for her,*

*but that two percent I still feel.*

*You don't have many of them and I probably only have one every two or three years*

*that's as far on that pole*

*but that means I've had twenty of them and you can remember every one of them.*

*I could just about recount the whole clinical course."*

This story opens with Dr Z orientating the situation as infrequent and contingent to a category of patients who are mostly men, denying death. Research suggests patients often find it very difficult to challenge doctors due to the institutional power they have (Lupton 1997). Dr Z does not consider his private patients' profile with regard to wealth to be too dissimilar to those he treated in the public system because health insurance schemes are more readily offered by employers and prioritised by patients. The patients Dr Z describes in this narrative however, suggest age, gender and possibly social class may be factors in redressing the asymmetry of power in their relationship.

The patients he describes appear powerful and their sense of self undiminished by the fact their body needed for "being-in-the-world" is diseased (Filc 2006, p. 240). Ironically these are patients who have taken up the socially ascribed and medically facilitated challenge to fight for their survival. They have chosen to ignore dominant discourses on the right way to die; their meaning-making critical to a 'good death' is to never give up. Their self-determined dying trajectory runs counter to the medically determined timing of when to give up the fight and in doing so, inverts the role of the clinician to passively having nothing more they can do. The journey is terminated and the ritual transformation is incomplete (Zimmermann 2007). Dr Z describes feeling 'disempowered' in these situations because he "hasn't been able to get through" to his patients.

Dr Z: "*... it's as though you're speaking a foreign language. Whereas I was brought up in xxxx; I learnt to communicate in the freezing works rather than at medical school. I just speak plain language and I have a reputation for that so it's not that I did it behind medical gobly-gook, it's just that I haven't been able to get the concept across or the concept hasn't been accepted because it's been rejected because of how that person sees the world and wants to maintain their integrity as a person often at the expense of how*

*the family will cope afterwards. So you feel sad and therefore you assume some of the sadness, I think, you assimilate some of the sadness."*

What is interesting in Dr Z's subtypes of distressing situations is that he has not blocked his patients' lifeworlds from the encounter (Barry et al. 2001). The relationship he builds with his patients could be considered empowering because they make their own views about their health and some will share these with him.

The refusal to accept the diagnosis and "gifts" of extending life Dr Z can provide positions his patients as non-compliant with the preferred treatment regime. Despite Dr Z's ability to communicate effectively with a wide range of people he cannot get this concept across. He hears their responses as rejection of the awareness and acceptance that is considered integral to the concept of a good death. However he acknowledges his patient's right to control their own dying as this is "how that person sees the world and wants to maintain their integrity". The tension in the shift to concordance in public health policy is evident in this situation. This assumes a respect for differences discussed openly and rationally in the context of an equal alliance but critiques suggest concordance retains a focus on changing the patient's attitudes (Bissell, May, and Noyce 2004). Brought to a conclusion in this situation, concordance can also mean negotiation may fail and in the end the patient and doctor agree to differ (Bissell, May, and Noyce 2004).

Whether Dr Z's response is borne from a paternalism and his "exaggerated sense of wanting to do good" for his patients and their families is questionable. There is definitely a concept Dr Z is trying to "get through" to modify his patients' beliefs but he is positioned within the medical management of death on society's behalf to do just this. He is left with few options but to try to change his patients' beliefs if not for them, then to ease the suffering he has witnessed loved ones experience in similar situations. When he cannot achieve this, Dr Z feels he has not done well and he is "letting that patient down or letting that patient's family down somehow."

There is a cumulative account of the number of encounters over the course of his career which reinforces the impact on him. He cannot forget each time this happens:

*Dr Z: "I think probably interestingly I often feel that I have failed in that setting that I haven't been able to bring that patient, person around to an acceptance that was still maintaining dignity for him or meaning but would have made it so much easier for his wife and family. And very peripherally would have made it a hell of a lot easier for me because interestingly your diastolic blood pressure goes up five points every time you look and say, 'Oh yes he's coming to see me tomorrow and I don't know quite what he's going to say.'*

*Often there can be a bit of anger in that patient's reaction, so yes they want to know but don't want to know."*

Dr Z spoke of his experiences from a position within, and across, the span of his career as an oncologist. Dr Z has established his reputation in the city he was born and raised in. He reflects on his differences to many of his medical colleagues in a way that suggest it is a mark of pride. He came to medicine from a different background where learning to adapt how he communicated to people from all walks of life was essential to his success. Unlike his colleagues who came from "posh schools" he has been able to use his disadvantage of wealth and status to advantage; he does not hide behind "gobly-gook" but faces his patients offering and receiving "gifts" his colleagues may never receive.

Dr Z's narrative style is as important to the analysis of the content because it illustrates how he can be successful at "bringing people around." Often during the interview he would pose questions to me at the end of a sentence, seeking agreement with the statement he has just made. He invited my assent to his experiences, concluding with questions like, "...and it's lovely isn't it?" and "...that's really rather wonderful isn't it?" It was impossible not to concur that the feelings of love and appreciation he experienced from his patients were lovely and wonderful. I realised at the end of the narrative how effective this technique would be if I was a patient he was talking with and began to understand how persuasive this was combined with his quiet voice and confident but gentle command of the conversation. It also reflected how this technique was integral to his performance and when the negotiation with his patients fails how limited the scripts are for him to extend the care he deeply wishes to provide.

Similarly in the final narrative of this chapter, Dr K is unexpectedly left with little to offer his patient when he is able to control her seizures so she and her loved ones can experience the peaceful death they may have been expecting from hospice care.

### **Narrative 3: Dr K**

In the literature on the medicalisation of death and dying Chapple (2010, p. 112) talks of the "derangements" to a good and orderly death when dying occurs at the wrong place or the wrong time. Dr K's narrative provides an insight into the emphasis on control of physical symptoms inherent in the "domestication" of dying assumed in hospice principles (Chapple 2010, pp. 110–111). For Dr K the responsibility to facilitate the good death weighs heavily on him as dying is "a situation that has inherent lack of control on the part of the patient and family and I feel that."

*"And there was nothing I don't think I could have done*

*I'll never forget a patient who had seizures.  
 She had a brain tumour and she had seizures  
 and the seizures were under control with anti-convulsants  
 but then she had this huge seizure  
 and she died having a seizure.  
 Status epilepticus is the term, people die from status epilepticus.  
 And there's just nothing that I gave in ten minutes  
 that stopped that seizure  
 and her partner was in the room,  
 she was a youngish woman,  
 and it was, it was, (motions body writhing in seizure)  
 and just foaming  
 and it was awful  
 and that was one where I absolutely stayed in the room  
 and the nurse, two nurses, were just running back and forth  
 and they knew exactly what I was going to order anyway  
 so, trying to get this seizure to stop.  
 And it didn't.  
 She died having a seizure.  
 That was terrible.  
 And there was nothing I don't think I could have done  
 . . . and I thought afterwards  
 and talked to my colleagues, 'What on earth could we have done?'  
 The only thing if I could have maybe found a vein  
 and stuck in an IV and tried to do an IV  
 but even then,  
 it was only ten minutes,  
 it was over in ten minutes,  
 but it was a terrible ten minutes."*

He opens this narrative with a statement of the significance of the situation he is going to describe; it is unforgettable, marking it as immediately distinct from other more routine situations. Like Dr's B and Z, this suggests Dr K wants to ensure I know this is uncommon and therefore his presentation in

this situation is acceptable. He allows me to see behind the scenes or at least watch from the wings but not necessarily get backstage (Goffman 1959).

Dr K orients me to the scene with a summary of his patient's symptoms, the management of those symptoms and the event of her death. He rounds this summary off with the definitive diagnosis of her condition, in Latin terminology to emphasise the condition can be fatal. This sets the scene for his actions and why he is unable to control his patient's seizures. He introduces two important features of this narrative; the temporality of his patient's dying and an audience, her partner is in the room. This follows with a return to his patient who he recalls as being a youngish woman. As he moves on to describe what was happening to her body he becomes animated, using his body to dramatise the seizures and the detail of her foaming at the mouth to illustrate the horror of what was happening before him.

In this and other situations where death is difficult, Dr K makes a point of his decision to stay in the room, referencing an earlier conversation when he talked of how it was often more likely to be the nurses who stayed. Again, this signals it is an out-of-the ordinary encounter demanding his presence. He is committed to trying to stop the seizures and now introduces more people to the scene. His performance is assisted by the team; two nurses are working with him and the tempo of his narrative increases as he describes them running to get what they anticipate he needs (Goffman 1959). His description indicates the hospice staff could be more accustomed to difficult deaths than Dr K's narrative suggests. He describes a scene reminiscent of the research conducted by Page and Komaromy (2005, p. 304) observing the medical response to an unexpected death where staff follow their professional scripts from "an affinity with the moral obligation of the performance". Dr K's narrative describes attempts to bring order to the chaos unfolding before him. His actions in managing this difficult situation suggest it is an expected response by his team to his patient's dying process and as such, no matter how futile, he must continue to intervene (Page and Komaromy 2005; Chapple 2010).

The action stops when unable to control the seizures his patient dies. He repeats the outcome again from the opening summary. Unable to control his patient's seizures the scene Dr K describes is one of panic and horror. Her body has defied his plans and he is unable to secure a peaceful death for her and her partner who is watching. It is terrible. Like Dr B, he experiences a sense of powerlessness. Dr K's intense activity to stop his patient's seizures is indicative of the response to a failed good death script Page and Komaromy (2005, p. 304) describe:

*"... death is still viewed as awkward in some way and that it needs meeting with the correct response and performance. In the westernised world this response is essentially medical and professional."*

The promise of a good death is unfulfilled and Dr K questions how he

could have done something different to achieve this. He shares this with his colleagues, and in ways not dissimilar to Dr B, this seems to be only about the technical management of his patient's physical symptoms. His return to more medical interventions seems to be all that is possible for him to consider. He concludes his narrative of the scene with his dying patient to a return to the temporality of her death. The time seems distorted by the terror he experiences; "it was a terrible ten minutes." In Dr K's stories of difficult deaths I was struck by the assault on his patients' bodies not only from the seizures, the pain or the bleeding, but the medical interventions Dr K was "throwing" at them.

I wondered how his patients' deaths would be managed if they were dying at home? I found it difficult to reconcile the "alternative script" of death in hospital espoused by the hospice movement with the biomedical interventions Dr K enacted (Page and Komaromy 2005, p. 295). I was reminded of Chapples's (2010, pp. 110–111) view on the modern day "deathwatch":

*"What was once called the deathwatch is uncomfortable for persons accustomed to goal-directed activities. Pressure exists to minimise one's exposure to such helplessness."*

For Dr K despite the futility of further medical intervention his reflection on these terrible moments indicates always having something more he can do for his patients is firmly within the biomedical model as he considers how he could have gone further and "stuck in an IV". The question is how he could do anything else when he is tasked with minimising exposure for his audience to the "series of destructive events" in the body's process of physiologically letting go that is the act of dying (Nuland 1994, p. 17).

## Demoralisation

If the dominant discourse of medical professionalism expects stoicism and rationality, what might the consequences be for the clinician who feels, expresses, and is deeply affected by emotional responses to disclosing a terminal diagnosis? Conversely, what are the consequences if they don't? An inability to bear the psychological and physical endurance expected, risks disrupting not only the professional norms but also the social order of medicine that expects a social good model of medicine to prevail (Bradby 2009). Reinforcing normative behaviour and stigmatising deviance is the norm and sets up the potential for substantial risks for the clinician. Few dare to disclose their own emotional pain or reaction lest it be considered irrational and an impediment to their technical competence as a doctor. This brings into question how clinicians can sustain the increasing frequency of diagnosing, communicating and managing their patients' life-limiting diagnoses in this complex and dynamic social world.



From Dr B's narrative there is no indication that he would see his patient again and this abrupt end is not discussed in relation to how his patient may feel after their five year clinical relationship is over though research on patient's perspectives confirms many feel abandoned, fearful, and isolated when this happens (Kasket 2006b). The fragmentation of medical care into specialities makes it difficult for practitioners to maintain continuity in their relationship with patients and let alone, be in a position to acknowledge the end. Time is rarely available for clinicians to visit dying patients outside of the hospital environment and as death nears, many patients are physically unable to attend clinics. Frank (2004, p. 86) contends how medicine is organised and resources allocated, contributes to the demoralization of medicine so "who gets how much of these is no longer organized according to the hypervalue that the physician's presence, in itself, can be healing".

For some clinicians, this facilitates avoiding a difficult and possibly emotional conversation with their dying patients but it can also be a deeply rewarding experience which can assist with their grieving (Back et al. 2005). However, this may be the last most important thing clinicians can do for their patients that would bring comfort, closure and a chance to say thank you (Back et al. 2005).

In a paper on physician grief, one oncologist described the sudden discovery and subsequent disclosure, of one of his favourite patient's cancer relapses, as an event which triggered emotion and introspection that acted like an "earthquake" reverberating through his holiday weekend (Shanafelt et al. 2014). Yet, the impact of this grief on the physician is rarely acknowledged or expressed, often leading to burn-out, depersonalisation and emotional exhaustion (Shanafelt et al. 2014). Dr B's sudden discovery of his patient's terminal diagnosis is the defining moment in his narrative and one he returned to several times. When he recalls the scene his thoughts are punctuated with hesitation as he seems to search for the words to describe how he feels. He does not use the first person throughout this narrative when he is talking about how he felt, suggesting his feelings are externalized by a rigorous internal emotional supervision where grieving is considered a severe breach of the rules (Kasket 2006b).

Dr B: *"Well I think you get relatively numbed to it as would be my experience. I don't think that means that you lose your empathy with the patient but I think ...Because this is what you're dealing with and this is what you do. I mean I think that for the average punter coming in with their newly diagnosed breast cancer I would think that in the overwhelming majority of the time, in terms of how I internalise it, that I'm emotionally neutral and in the overwhelming majority of cases, completely unaffected by it. There is the occasional case which you'd have to be personality disordered not to be...the lady who was a week post-partum; you'd have to*

*be sub-human not to be affected by that but happily things of that nature are very rare."*

Dr B's narrative suggests there would never be a situation where his emotions are not carefully managed and if he was troubled, it would be inappropriate to discuss this with other medical professionals; mirroring the "conspiracy of silence" Wallace (2010, p. 7) refers to in her research:

*"The tendency among many impaired physicians and their colleagues is to believe that the physician will either work it out or the problem will somehow disappear. Out of loyalty and respect, colleagues will often feel they owe one another the opportunity to resolve the situation on their own."*

In contrast to Dr B, Dr Z talked about the "cumulative battering" he experiences from dealing with dying patients most days. Alongside the cumulative battering, Dr Z talks of experiencing a "cumulative grief." For the most part it is grief he can cope with, with the exception of the few times with patients "where I feel as though I've not got through and therefore I should have done better somehow." He talks of "assimilating the sadness" from these situations but it is the relationship with his business partner and colleague that is a source of mutual and informal support. He questions if other oncologists really are coping or if this is more about maintaining "the brave face in the milieu that doesn't allow you to say, 'I'm grieving' or 'I'm a bit battered' without getting a seemingly 'Chopper Reid' response back."

Similarly, Dr V talks of the "vicarious distress" that he sees in medical colleagues from "sublimating distress, sadness, your own issues around suffering" as a factor in clinicians detaching from patients and no longer recognising them as people. Closely positioned as a trusted advisor, he is able to see from the outside his colleagues' responses to patients that are dying and is concerned that without being able to talk about their own feelings of sadness and grief, the care of the dying patient can be compromised:

*Dr V: "So people in ICU or people on crash teams that deal with cardiac arrests, I've had many conversations with people here about how hard it is for them to stop ventilation or to continuously walk away and not talk about it, and it gets hard to the point where you detach or you don't think about the person as a person anymore."*

He also thinks it is important clinicians give themselves permission to know that sometimes they won't succeed, to know that "sometimes there are things that just aren't flexible, sometimes there is no thing that's going to make it all go away." His views echo those of Frank (2004, p. 6) who asks "how do we accommodate our lives to what we can never cure, ultimately death?"

This is sentiment that Dr X also shares, saying there is an expectation that clinicians must appear as all-knowing to their patients but she thinks it is important for both the clinician and the patient to show some vulnerability in the process of disclosure:

Dr X: “...and I think really it’s a reflection who delivers it rather than anything else. I don’t think it’s even about not caring about the person they’re delivering it to; I think it’s more about how somebody feels ok in themselves. Whether they’re comfortable, whether they feel ok about being challenged, whether they feel ok about somebody bursting into tears in front of them. And clearly a lot of people don’t feel ok about that and maybe that’s something we need too. I don’t know, maybe some people would disagree, maybe some people would say that we don’t need to feel ok about that, but I think that you’d find that a lot of patients would prefer it if people showed their sense of vulnerability more in the conversation.”

Finding support within the dominant medical culture to take risks and show vulnerability is not easy. It brings to mind a theme from the literature where the system of institutionalised medicine is charged with alienating the doctor from their patient. As Frank (2004, p. 4) offers, “Too many people in medical settings, patients and staff both, are isolated from one another even as they work, suffer, and hope in the most intimate synchrony”. Dr K speaks of this when he compares his experience of working in palliative medicine with previous experiences as a GP:

“Dr K: That whole concept of safety, you know, people, practitioners have to feel safe to be able to expose their vulnerabilities

Jo: So if you didn’t have that feeling, in other places that meant that if you weren’t sure; it perhaps wasn’t safe to say?

Dr K: Yes, you would feel much more, isolated.”

Dr K’s response to the need to feel safe to express vulnerabilities highlights the sense of risk inherent when clinicians choose to act in ways that challenge their socialisation to the medical profession’s expectations of what is acceptable in the disclosure process. Dr B talked of the overarching fear of a formal complaint because of medical mismanagement yet Dr Z shared with me that in his experience as a member of the complaints board a large number of complaints were directly related to how clinicians had communicated and interacted with patients. The question is how can clinicians be supported so the fear and risk of acting with generosity and expressing vulnerabilities it seems almost abnormal to suppress are excised?

## Conclusion

Understanding the particular; the details of specific clinical encounters clinicians shared with their patients, these narratives moved the clinicians' experiences of disclosure beyond the generalities in Chapter 4 to the challenging terrain of their own and their patients' lifeworlds. Unlike the diagnosis narratives, their patients were present, and as such, introduced the uncertain, the unpredictable and the resistance silenced in the front stage presentation of the routine diagnosis. These difficult experiences seemed to overshadow the clinicians' successful routine encounters with their patients when a life-limiting illness is diagnosed, a prognosis offered and the hope of a meaningful and good death extended. This is the risk that clinicians seek to manage each time they are with a patient in these situations. Controlling medical uncertainty is what they are trained to do, however when the uncontrollable happens it is problematic and carries a toll.

There is an emotional impact and no matter how well they are buffered by the diagnosis process or endless medical interventions, or their powers of persuasion, it is palpable. Understandably, all of clinicians are vulnerable to the cumulative battering, as small numbers of difficult situations mount up over the course of their careers. Awareness of the risk of burn-out from assimilating the distress seems to offer little resistance to the dominant discourses of stoicism their vocation demands. It is hard to imagine the resistance it would take to choose to respond to dying and death differently in a medical culture not immune from bullying and isolation. If clinicians are constantly surveying themselves and other colleagues what opportunities are there for them to stop and listen to how their dying patients are really feeling? Yet, in the midst of demoralising systems and practices in medical care are stories from the clinicians who did just that and as such, provide the impetus for the narratives of generosity in the next and final chapter.

## Chapter 9

# “Remoralization”—narratives of risk and generosity

### Introduction

*“The traditional idea of medicine is to offer more than treatment. The hospitality that exceeds treatment welcomes the sick person without qualification. Medical hospitality invites the ill to feel less stigmatized and isolated. According to the ancient ideal, those who make medicine their work are to find their consolation in being the kind of people who offer such hospitality”. (Frank 2004, p. 3)*

Reading the clinicians narratives in the preceding chapters the distance between “the traditional idea of medicine” and the experiences they retell is not one of intent but rather of people who have sought to make a difference, within a system of care and profession responding to expectations of staving off death, always having a medical response and managing dying so it meets the ideal of the good and peaceful death; a concept more reconcilable to those of us yet to face this than the largely undignified disintegration of physiological systems Nuland (1994) described.

From the analysis of the clinicians’ narratives it would be plausible to conclude this thesis with a summary of how disclosure of terminal diagnosis or prognosis is more than telling and how clinicians’ telling is influenced by a powerful context of cultural, social and professional expectations. However, in the midst of the routine disclosures, the suffering, the frustrations and failures I heard other narratives I could not ignore or discount. These narratives were more pieces of the stories, rather than the plot, offered with humility and an abiding respect for the people involved; be they patients, families, colleagues or employers. They speak of risk, vulnerability, humanity and an unmistakable generosity. Collectively their pieces of stories build connections to a way forward where clinicians are supported to be the kind of people

they were when they embarked on a journey to help people and offer society’s hospitality to the sick (Frank 2004, p. 3).

Drawing on the work of Frank (2004) I present these narratives of risk and generosity as insights into how clinicians and their patients’ experiences of disclosure of a terminal diagnosis or prognosis can be remoralised. I conclude this final chapter of the analysis with some thoughts informed from the clinicians’ narratives on the broader social responsibilities and opportunities to extend generosity to those we ask, on our behalf, to bear witness to so much suffering.

## Care That Connects

Frank (2004, p. 84) argues remoralisation requires a “medicine that does not isolate but connects”. But what does that really mean for clinicians and their patients? How can clinicians know they are connecting with patients and how is this different to the care they might otherwise provide, or the care they witness peers and superiors providing? In response to these questions I found pieces interwoven into the clinicians’ experiences of disclosure that speak of a connection to the shared humanity and possibly mortality between the clinician and their patients. I begin with Dr X who recognises and positions her patients as people; in doing so, she affords them an equitable capacity to be able to judge when care is authentic. These excerpts are followed by Dr K’s story of learning another way to connect from watching nurses caring for their patients. The last narrative of this section is Dr Z’s poignant stories offering final reassurances to his patients.

## People Can Tell

From the beginning of the interview Dr X’s narratives of her disclosure experiences were characterised by her sense of injustice when the rules of medicine dictated how dying patients were treated and how she felt powerless as a medical student to challenge them directly. Yet, Dr X does take risks, and acts from a strong value and belief system to extend care and empathy to patients when others have abandoned them:

Dr X: *“So I went and talked to this woman because everyone was shut off from everyone and she was just on her own and I had a real sense of again, this doesn’t feel right to me to come and what seemed like a matter-of-fact presentation of, ‘Actually you’ve got something nasty and you’re going to die’ kind of idea...but thinking, ‘Oh I can’t just go and pretend I haven’t heard it.’ I don’t even mean that, it’s more like I couldn’t leave, something in me would not let me leave because I felt like this woman needs somebody to at least engage ...*

*But interestingly I got in trouble for that... because someone said to me 'What makes you think that it's your job to do this?'"*

Dr X also talked of a big expectation to “know lots of stuff” but questioned the validity of this from the perspective that doctors are “not really encouraged or allowed to be in the position where you feel comfortable about not knowing things.” She suggests this contributes to why doctors deliver bad news “standing up at a bedside without a heck of a lot of compassion or bedside manner.” For Dr X really getting to know somebody requires thinking beyond asking the questions she has been trained to do in the focus on symptoms and try to really engage with people:

*Dr X: "... ask what your inclination is, where does your mind take you about these kind of things? And I think that you end up finding about who a person is and what they want or what they need in a situation rather than the catch all six out of eight or whatever."*

However she recognises the omnipresent medical culture can mean taking risks to be able to engage with patients this way, particularly when the technical voice of medicine is given much greater authority:

*Dr X: "But I don't think the system so much allows you to be that way and so I do think that you have to be brave or whatever, that's my sense to speak out because it's a far more rational kind of thing."*

The rational, pragmatic voice of medicine is challenged by Dr X who seeks to infuse her own lifeworld values into how she communicates with her patients. Communication is not just a set of techniques to elicit specific responses rather, for Dr X it is finding a way to connect with her patient and also be open to what their response may be. Unlike doctor-patient encounters where the voice of medicine dominates and patients quickly learn what responses are expected and affirmed by the clinician, Dr X is comfortable with the uncertainty of how her patients wish to respond. As such, she credits her patients as an audience with insight into the authenticity of her performance and in return experiences their generosity of forgiveness if she does not always perform perfectly:

*Dr X: "I think a lot of it is that people can really tell whether or not you're genuine in the way that you deal with them and I believe that's a really important thing and I think that people can see through that really well so I think people are forgiving."*

Forging connections with patients so medicine does not isolate them, Dr X talks of trusting her “unique-self”, being both “brave” and “curious” to question “why this might be the way it is?” Her narrative resonates strongly

with Frank’s (2004) concept of remoralisation for patients and clinicians alike. Sadly, in her experience this takes bravery to risk others’ reproach so she can still be her “unique self” and a clinician.

## Touch

Communication techniques are afforded a dominant place in the literature on how to break bad news to a patient. Much of this literature however assumes techniques and models of communication will be successful no matter who the audience is. In this way, the status of the voice of medicine remains intact because techniques offer pre-determined scripts to manage and control difficult conversations without premising how unique the experience is for the patient. Notwithstanding guidance on how to communicate to patients is critical and at least allows medical students and clinicians the opportunity to reflect on what the purpose of their communication may be in disclosure moments.

As a strong advocate for the utility of communication skills training and techniques, Dr K talks of how much he has integrated into his interactions with patients so he can facilitate conversations about dying patients are reluctant to have with others. He provides many hypothetical examples of how this would work; however it is when he is sharing a story of an experience with a patient that his commitment to connecting openly and honestly with them is so apparent. In this narrative Dr K talks about how he learned the importance of touch:

Dr K: *“The other thing that’s real important in communication skills that I had to learn with time, and I learned a lot from what I observe in nursing and what nurses say is that physical touch is a hugely important way. That distance between clinician and patient disappears and patients ask things when there’s touch involved that they wouldn’t ask necessarily when there’s no touch involved. So nurses will say that here when they’re doing physical care, they’re giving somebody a bath or a wash, stuff comes out from patients about what they’re worried about, what they’re upset about, you know...”*

His story is a refreshing inclusion to the repertoire of verbal communication techniques and a compelling example of how patients as people, can be reached without words:

*“I’ll never forget this patient, a year ago or so;  
woman came to an outpatient clinic here from work.  
She was single, great career, she lived in Turkey and Italy and New York and all these places all over the world.  
She had advanced cancer and she continued to work.*



*She came in here for an outpatients clinic and she sat like this  
 (arms folded across chest)  
 and she was giving me her story  
 and I was doing the doctor thing, talking ra, ra, ra  
 and I said: 'I need to examine you.'  
 I took her round to the examination room,  
 sat her on the edge of the bed,  
 put the blood pressure cuff on,  
 I had the stethoscope in my ears and I was doing her blood pressure  
 and she said: 'I just want to die.'  
 So it was just when I was touching her,  
 I was just doing the blood pressure, wasn't even undressed right?  
 So it's... like 'tell me what you're thinking' or 'what's that about?'  
 Or whatever, exploring from right then because it was the touch.  
 When we weren't touching  
 it was very much the resolve, you know,  
 professional to professional really.  
 But the moment of touching was (intake of breath)..."*

Interestingly in this narrative Dr K again orients me to his patient's identity as a professional; an identity he shares with her. His description of where and how she works builds a picture of her self-reliance and stoicism in the face of advanced cancer. This picture seems to show not only a connection with her but also an admiration of her. However there is also a sense her emotional response is permissible because she ordinarily would respond as a professional, suggesting when she does respond as a patient with advanced cancer who is feeling overwhelmed, it is a surprise.

Dr K's orientation builds the case of the power of touch. Not only can this physical connection break down her stoicism and expectations of how she should behave as a professional it also enables her to move beyond an intellectual response to talk about how terrible she is feeling. What is important is how Dr K responds to her. Identifying as a professional he could have continued doing his doctor thing, returning her attention to her physical symptoms and effectively closing down the passageway where they can connect (Frank 2004). Rather, Dr K stops doing - it is critical to his story and remarkably different to his other narratives of his experiences with patients dying. He has the courage and humanity to explore her response, opening the space for her to share what he intuitively from her body language is being tightly held within.

It is understandable that for many people with life-threatening illnesses, the expectation to find the words to express what they are feeling in the face of adversity is too difficult, particularly if there are no words to describe this meaningfully to another person. Furthermore, their sense of aloneness and isolation can be exacerbated when the expectation is they speak only words of bravery and a valiant struggle rather than acquiescence. The connection to things beyond the intellectual can sometimes only be accessed through touch. The same could also be said for clinicians.

### On saying goodbye

There is a greater sense of intimacy and affection in Dr Z’s clinical relationships. He talked of going to visit patients in their home or hospice when death was near and recognised the comfort this brought to them and their families as well as the healing he felt. He finds it tough when patients are suffering existentially and offered a recent example of visiting one patient in hospice who was angry:

Dr Z: “...it’s harder if they’re suffering existentially  
so that’s the tough one.

*A recent example perhaps*

*a lovely man, very well-read, we shared books to read and that sort  
of thing*

*and I know I helped him a lot just cope with everything,*

*and he’d been a bit depressed on and off over his life*

*and that sort of stuff.*

*Well I saw him actually in the hospice a couple of days before he  
died*

*and he was quite angry. But all he was angry about was,*

*”How much longer do I have to be like this?”*

*And when I said, ”It’s not going to be much longer, you don’t have  
to endure this very much longer.”*

*And it wasn’t pain it was just suffering,*

*”I feel useless I can’t even do anything, I can’t even read anymore”,  
that sort of suffering.*

*And I gave him a hug and said,*

*‘it wouldn’t be very much longer.’*

*But all he was angry about was, ‘How much longer do I have to be  
like this? And when I said,*

*'It's not going to be much longer, you don't have to endure this very much longer.'*

*And I gave him a hug and said it wouldn't be very much longer.*

*He died two days later.*

*His wife rang up and said, 'He said to me Dr Z said I could go, it's okay now'*

*and she said, 'Thank you'.*

*Well again, getting that back takes away three months of cumulative grief I'm very privileged because I have bits of people's lives*

*and I get bits of love from lots of people*

*so that takes away most of the cumulative stuff I think."*

In the narrative above Dr Z takes time to connect with his patients and their loved ones even in difficult moments when they are suffering and dying is not peaceful. He is aware his presence can bring comfort and his words as one who has witnessed so much suffering, can ease his patient's burden. His generosity is reciprocated with a call from the man's wife thanking him and affirming his efforts to relieve his patient's suffering. Dr Z's experience exemplifies Frank's (2004, p. 99) assertion that "identification with the ill is not a burden added to what physicians already bear; it lightens what they must bear".

In response to this story I asked Dr Z if there were situations where he may actually be saying goodbye to someone. He describes how endings he can participate in assist his own preparation for the loss he may feel:

Dr Z: *"Yes, that's right and that's pretty tough. I guess I tend to see people, this may be some of the differences that you asked right at the very beginning between public and private, my public colleagues will say it's because of numbers of patients, but I used to do it there. If things were going wrong and life expectancy was relatively short, I would still see those patients, they would still come back to a follow-up clinic with me even though I might have obviously got palliative care involved and the GP and things like that. So I've got a lot of patients at any one time who actually are in the last weeks of their lives but they might be seeing the GP one week as arranged between the GP and myself, and me the next or something like that. Basically that's just part of the process of caring and so to some degree, it's a bit like getting the patient home before the eulogy, to some degree I've said goodbye as we're going along rather than I've heard about the death or read about the death in the notices in the newspaper. Which can otherwise be so telling – I do look at the funeral notices and then every now and then if*

*I hadn't known somebody was declining and I see it, I'm probably more affected than the ones I knew were because I'm less prepared for that one, whereas I'm prepared for the others.”*

Endings matter, yet few clinicians talked specifically of saying goodbye, even Dr K who at the very end with his patients never explicitly talked of this as part of what he was doing for them as they died (Gawande, 2014). In Dr Z's narrative feeling he has said goodbye prepares him for the loss he feels when a patient dies and there is sense of closure for the work he has done to help his patient and also the end of their therapeutic relationship. His narrative reflects a more modern version of the traditional care Frank (2004) refers to where he may not have the time for an extended death-watch at his patient's bedside but he recognises his presence alone can be deeply reassuring and healing.

*Dr Z: “There's a point where I would lose that contact because it's just inappropriate to bring them in because they're more bed-bound, I quite often visit people at home and families just love that. I'll visit somebody in the hospice or if it's somebody at home. I guess what that's done is that its helped me, there's probably quite a lot of personal healing going on by doing that because a family is so chuffed that a doctor's going to call past and just say hello and sit on the end of the bed and hold somebody's hand, you don't have to spend a long time there.”*

Dr Z's narrative is testament to the reciprocity generosity brings and how important opportunities to acknowledge endings are to his ability to keep doing what he does. When asking how we as individuals act to restore generosity, Frank (2004, p.137) contends responses “risk becoming lost in elaborations of institutional complications and menacing possibilities”. Dr Z's response is by contrast elegantly simple. There is still something more that can be done as a clinician and that is to honour the relationship he has with patients by recognising they mattered enough to him to face them as people and say goodbye.

## The Way Forward

If, as Frank (2004, p. 1) suggests, “Medical generosity sets a standard for the rest of society, because illness is a universal form of suffering” then who is responsible for ensuring the standards are set? Is this the sole responsibility of those who practice medicine? If so, how can the medical generosity described in this chapter infuse the medical socialisation of every medical student? Or are there broader connections to be made where society supports and reciprocates medical generosity, recognising not only the universality of illness but

the needs of those charged with caring for us? In response to these questions I present in this final section two excerpts from interviews with Drs V and K because they connect the generosity depicted in the clinicians' narratives above with a reciprocity within and outside the medical profession.

### **Reflecting Generosity From Within and Outside the Profession**

Dr V's role as a palliative care consultant in a large urban hospital extends beyond patient care to provide support to other medical practitioners. His insight into the suffering many witness in their daily working lives and the difficulties expressing the feelings this brings up is evident in his description of how he may support them:

*Dr V: "We are often sitting down and listening and working it through, and acknowledging it and we're working at that level with our colleagues. We'll get asked to go and see someone for pain control and go and sit down with a colleague and say, 'So what are the issues?' 'Well the pain's not under control and no matter what we do we can't help and it's so frustrating and it's really sad because they're young and I don't know what to say'. And suddenly it's not about the pain, it's about them and their feelings and how confronting this is for them and so that's a large piece of our work."*

Responding without judgement, Dr V extends a generosity toward colleagues who he has over the course of his career come to see as "good people doing the best job that they can and everyone's intention is to do the best by the patient." He understands difficult conversations may not always go perfectly but informed by his experience over his career and the concept of mindfulness he generates a context of kindness and acceptance toward them:

*Dr V: "I've never come across someone at this stage who doesn't just want to do the best and so sometimes it doesn't work out that the person's heard or understood because it's a factor to do with them or their family and sometimes it's to do with the way the news was delivered but I think that's just how life is."*

His perspective is a distinct and refreshing contrast from the literature critiquing clinicians for how they disclose a terminal diagnosis or prognosis. He is aware of the decisions his colleagues face and how hard it can be to communicate these when it feels like this will hurt the patient:

*Dr V: "That's a huge part of what we do in our service is supporting colleagues who are having these difficult conversations and who are*

*having to make difficult decisions and one’s that don’t sit easily with them because they don’t want to hurt someone or give up hope, or someone’s young and they feel that it’s not right that they should die so young and we need to do an extra bit whatever that might be. And of course there is no extra bit really because if someone’s going to die, they’re going to die.”*

However, Dr V also offers a generosity to what is expected of clinicians caring for patients who are dying. There is no “extra bit” that can stave off death and in reminding his colleagues of this allows room for mortality, their own and their patients, to be considered. It is an approach Dr V does not forcefully present but rather offers as his own awareness of the suffering inherent in his profession. The potential for how Dr Z influences the culture and medical socialisation of the junior doctors he teaches with his approach is in my opinion a powerful response to Frank’s (2004, p.1) challenge to “increase the generosity with which we offer the medical skill that has been attained”.

In this next example from Dr K the generosity he describes is from outside of the medical profession and offers a sense of the connection he feels when the care he and his team offer to those who are dying and their loved ones is reciprocated by others:

*Dr K: “But another thing I find sustaining is where yes, society denies, but there’s been a number of things, that young man with the horrible tumour on his face, his mother works at Pak n Save, she’s a cashier at Pak n Save. Pak n Save said to her: “Don’t come in to work, stay with your son”. They continued to pay her salary. I don’t know how many months they paid her, not great salary she’s a cashier but they paid her salary. No expectations that she would come in. I’m sure it wasn’t part of a contractual arrangement but they paid her salary for her to be at home with her son and it went on and on and on. That’s the kind of story which I find really inspiring. I think the Warehouse does that same sort of thing. And that’s nothing to do with the hospice. We also hear the awful stories of employers who sack people and some people come and they have no income and we have to negotiate with Work and Income to get the supports and da,da,da but we also hear employers who keep the income going. That keeps me going when I hear that sort of story where communities support the dying person.”*

The generosity extended by this employer exemplifies our shared humanity and responsibility to offer hospitality to those that are ill. Dr K is sustained by these responses from communities and “feels a part of it” indicating how connecting the work of medical professionals to society is integral to the remoralising Frank (2004) advocates. Hospice care is one vital link to communities

and in this respect more easily accommodates the flow of generosity between the medical profession and society. There is a higher level of visibility as a result, facilitating an opportunity for lay people to witness the complexities of caring for dying people clinicians must navigate every day. Although for privacy reasons he is unable to publically acknowledge the company for what they have done he can respond with a letter of thanks. What matters most to Dr K is that “as long as we are acknowledging to somebody in their chain that this is a really, really important and good thing.”

### Other Tangents...

Combating isolation, failure, fear of reprisals from patients, colleagues, senior clinicians and complaints authorities and becoming emotionally numb in clinicians who are tasked with disclosing life-threatening illnesses or prognosis is a challenge. I contend it is a challenge not just for the medical profession but for westernised society as a whole to face what death really is, understand what we are asking clinicians to do on our behalf, and find ways to forgive them and ourselves—the ultimate act of generosity (Frank 2004).

A significant step toward this would be to acknowledge what it is clinicians are being tasked with when they disclose a life-threatening illness or terminal diagnosis. If we accept disclosure is more than delivering a diagnosis to a patient and consider disclosure as the critical rite of passage to bringing people around to accepting the trajectory of medical care to follow, then it changes how clinicians can be supported to do this. Understanding disclosure as nuanced with social, cultural and professional expectations of clinicians managing patient responses to their newly altered future demands different responses. Firstly, repositioning clinicians as equally susceptible to emotional suffering as their patients, albeit cumulatively, presents a challenge to dominant discourses of stoicism and self-reliance. This raises questions of why the emotional well-being of clinicians is not granted the same primacy as it is in other models of professional supervision and competence such as psychiatry, psychology, and palliative care.

Dr Z suggests that if medical professionals are supported in “letting the cumulative and the occasional frustrations out, your competence is probably going to be enhanced anyway isn’t it?” Strategising on how this shift could happen in the medical profession, Dr Z pointed to the acceptance of the concept of palliative care in medicine and in particular how palliative care specialists are provided with professional supervision.

*Dr Z: “Sorry another tangent but the palliative care bit is interesting. That might be the way to make it more generalised because if we’re saying palliative care means the quality of life aspects of all of the chronic illnesses that we live with more because sixty-five percent of all of the people who ever got to sixty-five are alive today,*

*then having supervision across all of the disciplines in medicine that care for patients as opposed to diagnose might be actually pretty damn sensible.”*

Dr Z’s suggestion seems rational, pragmatic and logical, given the increasing complexity and blurred boundaries of life-threatening and chronic illnesses he identifies as a significant change in how clinicians care for patients. Given the influence of technological and demographic shifts, Dr Z is alert to the likelihood of more clinicians facing disclosure moments across a wider range of medical specialities. Applying Dr Z’s logic suggests there is an opportunity for emotional competence to be commensurate with other requirements of the continuing professional development for clinicians’ recertification:

*Dr Z: “You could say that, ‘We think supervision is important and we’d like evidence that you attended at least five sessions a year.’ Or something like that. I don’t think that would be that outrageous.”*

Affording an equal status to emotional well-being would go a long way to challenging the stigma of mental health Wallace describes in her research. After all these somewhat outmoded and unhelpful expectations of medical professionals reinforces discriminating discourses of mental illness as an individual failing. There is an inherent contradiction present for a profession who is charged with caring for those with mental illness but cannot extend the same understanding to their colleagues. In this respect, despite all the technological advances in medicine, the profession appears to one of the few remaining bastions of the “stiff upper lip” mentality.

It also follows that how clinicians are trained and supported to break bad news could encompass their own as well as their patients’ responses to grief and loss. This is not to suggest clinicians must always have an emotional response or connection to their patients when disclosing a terminal diagnosis or prognosis but rather to allow space for it to be possible. It is as likely there are patients who they do not connect with, who frustrate and enrage yet it is equally important they can discuss this without feeling guilty or uncaring also.

## Conclusion

Ultimately, from the clinicians’ experiences in this chapter, it is developing an understanding that at times such as disclosure and imminent death it is the power of connection which can heal both patients and clinicians. Learning how to connect beyond the prescribed models for breaking bad news requires the bravery evident in the clinicians’ narratives, to sit with the discomfort of not knowing what to do, of making mistakes, of not always having something



medical to offer, of understanding the value of stopping, holding a hand, being silent and not “miss the face” (Frank 2004, p. 116).

To achieve any of these things requires we who are not medical professionals to also act with bravery and face all of what death and dying is without expecting this will always be peaceful and always be good. Shifting our own expectations of death we may offer a generosity toward medical professionals so we are not asking them to tell the truth but mask the reality by always having something medically to offer. Clinicians may often be positioned as the intermediaries between life and death in the work they do but they are also the intermediaries in the cultural and social demands for managing death and dying. In this respect, we have a shared responsibility in how we ask them to do this and what can change.

All of the clinicians in this research cited the opportunity to have continuity in their relationship with patients as significant to their experiences of disclosure. This resonates with the literature on patient experiences, specifically not feeling abandoned during the transition from cure to palliative care. Yet medical care is increasingly structured into specialisms which fragment doctor-patient relationships and the opportunity to connect at such critical times. There are a multitude of reasons why changes to the structure of medical care is not possible but this does not mean it cannot be modified to allow time for clinicians to continue to see patients who may be under another clinicians care. What it requires is the value of the healing presence of the clinician to be included in the commodification of clinicians’ time. Above all else this could facilitate the opportunity for disclosure of a terminal diagnosis or prognosis to be a point of connection for clinicians which can continue across the journey of their care to the end.

After all in the context of open awareness it seems illogical and disingenuous the system of medical care rarely extends to allowing time for saying goodbye.



# Bibliography

- Ahalt, C. et al. (2012). “Knowing is better: preferences of diverse older adults for discussing prognosis”. In: *Journal of General Internal Medicine* 27.5, pp. 568–575.
- Anderson, W. G., S. Kools, and A. Lyndon (2013). “Dancing Around Death Hospitalist–Patient Communication About Serious Illness”. In: *Qualitative Health Research* 23.1, pp. 3–13.
- Arbabi, M. et al. (2014). “Patients Preference to Hear Cancer Diagnosis”. In: *Iranian Journal of Psychiatry* 9.1, p. 8.
- Arráez-Aybar, L.-A., G. Castaño-Collado, and M.-I. Casado-Morales (2008). “Dissection as a modulator of emotional attitudes and reactions of future health professionals”. In: *Medical Education* 42.6, pp. 563–571.
- Atkinson, P. (1997). “Narrative turn or blind alley?” In: *Qualitative Health Research* 7.3, pp. 325–344.
- Atkinson, R. and J. Flint (2003). “Sampling, snowball: accessing hidden and hard-to-reach populations”. In: *The AZ of social research*. Ed. by R. In Miller and J. ( Brewer. London: SAGE Publications, Ltd, pp. 275–81.
- Back, A. L. et al. (2005). “On saying goodbye: acknowledging the end of the patient–physician relationship with patients who are near death”. In: *Annals of Internal Medicine* 142.8, pp. 682–685.
- Baile, W. F. et al. (2002). “Oncologists attitudes toward and practices in giving bad news: an exploratory study”. In: *Journal of Clinical Oncology* 20.8, pp. 2189–2196.
- Barnett, M. M. (2002). “Effect of breaking bad news on patients’ perceptions of doctors”. In: *Journal of The Royal Society of Medicine* 95.7, pp. 343–347.
- Barry, C. A. et al. (2001). “Giving voice to the lifeworld. More humane, more effective medical care? A qualitative study of doctor–patient communication in general practice”. In: *Social Science & Medicine* 53.4, pp. 487–505.
- Becker, H. S. (1993). “How I learned what a crock was”. In: *Journal of Contemporary Ethnography* 22, pp. 28–28.
- Becker, H. S. (1961). *Boys in white: Student culture in medical school*. Chicago: University of Chicago Press.

- Bissell, P., C. R. May, and P. R. Noyce (2004). "From compliance to concordance: barriers to accomplishing a re-framed model of health care interactions". In: *Social Science & Medicine* 58.4, pp. 851–862.
- Blows, E. et al. (2012). "Liminality as a framework for understanding the experience of cancer survivorship: a literature review". In: *Journal of Advanced Nursing* 68.10, pp. 2155–2164.
- Boland, T. (2013). "Towards an anthropology of critique: The modern experience of liminality and crisis". In: *Anthropological Theory* 13.3, pp. 222–239.
- Boyle, F. M. et al. (2004). "Cancer: communicating in the team game". In: *ANZ Journal of Surgery* 74.6, pp. 477–481.
- Bradby, H. (2009). *Medical sociology: an introduction*. London: SAGE Publications.
- Broom, A. et al. (2014). "The Troubles of Telling Managing Communication About the End of Life". In: *Qualitative Health Research* 24.2, pp. 151–162.
- Brown, P. (1995). "Naming and framing: the social construction of diagnosis and illness". In: *Journal of Health and Social Behavior*, pp. 34–52.
- Brown, P., M. Lyson, and T. Jenkins (2011). "From diagnosis to social diagnosis". In: *Social Science & Medicine* 73.6, pp. 939–943.
- Callahan, D. (1993). *The troubled dream of life: living with mortality*. New York: Simon & Schuster.
- (2000). *The troubled dream of life: in search of a peaceful death*. Washington, DC: Georgetown University Press.
- (2009). "Death, mourning, and medical progress". In: *Perspectives in Biology and Medicine* 52.1, pp. 103–115.
- Carrion, I. V. (2010). "Communicating terminal diagnoses to Hispanic patients". In: *Palliative and Supportive Care* 8.02, pp. 117–123.
- Chapple, H. S. (2010). *No place for dying: Hospitals and the ideology of rescue*. Walnut Creek, California: Left Coast Press.
- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. London: SAGE Publications.
- Charmaz, K. and V. Olesen (1997). "Ethnographic research in medical sociology its foci and distinctive contributions". In: *Sociological Methods & Research* 25.4, pp. 452–494.
- Charo Rodriguez, M. et al. (2011). "A Historical Essay about Notions of a Good Death: Toward Shared Decision-Making at the End of Life. Presented as a plenary talk at the 1er Congr Francophone d'Accompagnement et de Soins Palliatifs in Lyon, France". In:
- Charon, R. (2001). "Narrative medicine: a model for empathy, reflection, profession, and trust". In: *JAMA* 286.15, pp. 1897–1902.
- Cochrane, J. B. et al. (1991). "Death anxiety, disclosure behaviors, and attitudes of oncologists toward terminal care". In: *OMEGA-Journal of Death and Dying* 22.1, pp. 1–12.

- Conrad, P. (1985). "The meaning of medications: another look at compliance". In: *Social science & medicine* 20.1, pp. 29–37.
- Craib, I. (2003). "Fear, death and sociology". In: *Mortality* 8.3, pp. 285–295.
- Creswell, J. (2009). *Research design: Qualitative, Quantitative, and mixed methods approaches*. London: SAGE Publications.
- Davenport, N. H. (2011). "Medical residents use of narrative templates in storytelling and diagnosis". In: *Social Science & Medicine* 73.6, pp. 873–881.
- Detsky, A. S., S. R. Gauthier, and V. R. Fuchs (2012). "Specialization in medicine: how much is appropriate?" In: *JAMA* 307.5, pp. 463–464.
- Dew, K. (2000). "Deviant insiders: medical acupuncturists in New Zealand". In: *Social Science & Medicine* 50.12, pp. 1785–1795.
- Dickinson, G. E. and R. E. Tournier (1994). "A decade beyond medical school: A longitudinal study of physicians' attitudes toward death and terminally-ill patients". In: *Social Science & Medicine* 38.10, pp. 1397–1400.
- Dickson, D. et al. (2002). "Health professionals' perceptions of breaking bad news". In: *International Journal of Health Care Quality Assurance* 15.7, pp. 324–336.
- Dimoska, A. et al. (2008). "Perceived difficulties in consulting with patients and families: a survey of Australian cancer specialists". In: *Medical Journal of Australia* 189.11-12, pp. 612–615.
- Dwyer, S. C. and J. L. Buckle (2009). "The space between: On being an insider-outsider in qualitative research". In: *International Journal of Qualitative Methods* 8.1, pp. 54–63.
- Field, D. (1996). "Awareness and modern dying". In: *Mortality* 1.3, pp. 255–265.
- Field, D. and G. Copp (1999). "Communication and awareness about dying in the 1990s". In: *Palliative Medicine* 13.6, pp. 459–468.
- Filc, D. (2006). "Power in the primary care medical encounter: Domination, resistance and alliances". In: *Social Theory & Health* 4.3, pp. 221–243.
- Frank, A. W. (1995). *The Wounded Storyteller: Body, Illness, and Ethics*. Chicago: The University of Chicago Press.
- (2004). *The renewal of generosity: Illness, medicine, and how to live*. Chicago: University of Chicago Press.
- Frankenburg, R. (1992). *Time, health, and medicine*. London: SAGE Publications.
- Friedrichsen, M. and A. Milberg (2006). "Concerns about losing control when breaking bad news to terminally ill patients with cancer: physicians' perspective". In: *Journal of Palliative Medicine* 9.3, pp. 673–682.
- Gawande, A. (2014). *Being mortal: Medicine and what matters in the end*. London: Profile Books.
- Gee, J. P. (1991). "A linguistic approach to narrative". In: *Journal of narrative and Life History* 1.1, pp. 15–39.

- Gee, P. (2011). "Approach and Sensibility: A personal reflection on analysis and writing using Interpretative Phenomenological Analysis". In: *Qualitative Methods in Psychology Bulletin* 11, pp. 8–22.
- Gee, P. (1986). "Units in the production of narrative discourse". In: *Discourse Processes* 9.4, pp. 391–422.
- Glaser, B. G. and A. L. Strauss (1965). *Awareness of dying*. New Brunswick, New Jersey: AldineTransaction.
- Goffman, E. (1959). *The presentation of self in everyday life*. New York: Anchor Books Doubleday.
- Good (1994). *Medicine, rationality and experience: an anthropological perspective*. Cambridge: Cambridge University Press.
- Good et al. (1994). "Oncology and narrative time". In: *Social Science & Medicine* 38.6, pp. 855–862.
- Gordon, E. J. and C. K. Daugherty (2003). "Hitting you over the head: oncologists disclosure of prognosis to advanced cancer patients". In: *Bioethics* 17.2, pp. 142–168.
- Grassi, L. et al. (2000). "Physicians' attitudes to and problems with truth-telling to cancer patients". In: *Supportive Care in Cancer* 8.1, pp. 40–45.
- Grönlund, C. E., V. Dahlqvist, and A. I. Söderberg (2011). "Feeling trapped and being torn: Physicians' narratives about ethical dilemmas in hemodialysis care that evoke a troubled conscience". In: *BMC Medical Ethics* 12.1, p. 8.
- Guest, R. S. et al. (2011). "Cancer surgeons distress and well-being, II: modifiable factors and the potential for organizational interventions". In: *Annals of Surgical Oncology* 18.5, pp. 1236–1242.
- Haas, J. and W. Shaffir (1982). "Taking on the Role of Doctor: A Dramaturgical Analysis of Professionalization\*". In: *Symbolic Interaction* 5.2, pp. 187–203.
- Hafferty, F. W. and R. Franks (1994). "The hidden curriculum, ethics teaching, and the structure of medical education." In: *Academic Medicine* 69.11, pp. 861–71.
- Hagerty, R. et al. (2005). "Communicating prognosis in cancer care: a systematic review of the literature". In: *Annals of Oncology* 16.7, pp. 1005–1053.
- Hak, T., G. Koëter, G. van der Wal, et al. (2000). "Collusion in doctor-patient communication about imminent death: an ethnographic study". In: *British Medical Journal* 321.7273, pp. 1376–1381.
- Hochschild, A. R. (2003). *The managed heart: Commercialization of human feeling*. Berkely: University of California Press.
- Hodkinson, K. (2013). "The need to knowtherapeutic privilege: a way forward". In: *Health Care Analysis* 21.2, pp. 105–129.
- Holstein, J. A. and J. F. Gubrium (2009). *Analyzing narrative reality*. California: SAGE Publications.

- Jackson, V. A. et al. (2008). "A qualitative study of oncologists' approaches to end-of-life care". In: *Journal of Palliative Medicine* 11.6, pp. 893–906.
- Jasperse, M., P. Herst, and G. Dungey (2014). "Evaluating stress, burnout and job satisfaction in New Zealand radiation oncology departments". In: *European Journal of Cancer Care* 23.1, pp. 82–88.
- Jespersen, A. P. and T. E. Jensen (2012). "Making consultations run smoothly: An analysis of doctors' skilful use of time inspired by science and technology studies". In: *Time & Society* 21.3, pp. 330–350.
- Johansen, M.-L. et al. (2012). "I deal with the small things: The doctor–patient relationship and professional identity in GPs stories of cancer care". In: *Health* 16.6, pp. 569–584.
- Jutel, A. (2009). "Sociology of diagnosis: a preliminary review". In: *Sociology of Health & Illness* 31.2, pp. 278–299.
- Jutel, A. and S. Nettleton (2011). "Towards a sociology of diagnosis: reflections and opportunities". In: *Social Science & Medicine* 73.6, pp. 793–800.
- Kasket, E. (2006a). "Death and the Doctor II A Phenomenological Investigation". In: *Journal of the Society for Existential Analysis* 17.2, p. 385.
- Kasket, E. (2006b). "Death and the Doctor". In: *Journal of the Society for Existential Analysis* 17.1.
- Kaufman, S. R. and L. M. Morgan (2005). "The anthropology of the beginnings and ends of life". In: *Annual Review of Anthropology* 34, pp. 317–341.
- Kleinman, A. (1988). *The illness narratives: Suffering, healing, and the human condition*. New York: Basic Books.
- Klenow, D. J. and G. A. Youngs (1987). "Changes in doctor/patient communication of a terminal prognosis: A selective review and critique". In: *Death Studies* 11.4, pp. 263–277.
- Kneebone, R. (2014). "Escaping Babel: the surgical voice". In: *The Lancet* 384.9949, pp. 1179–1180.
- Krisman-Scott, M. A. (2000). "An historical analysis of disclosure of terminal status". In: *Journal of Nursing Scholarship* 32.1, pp. 47–52.
- Kubler-Ross, E. (1969). *On Death and dying*. New York: Macmillan.
- Kuerer, H. M. et al. (2007). "Career satisfaction, practice patterns and burnout among surgical oncologists: report on the quality of life of members of the Society of Surgical Oncology". In: *Annals of Surgical Oncology* 14.11, pp. 3043–3053.
- Laranjeira, C. A., P. P. Leão, and I. Leal (2014). "Temporal Experience Among Women Gynecological Cancer Survivors A Lifeworld Perspective". In: *Affilia*, pp. 170–186.
- Larkin, M., S. Watts, and E. Clifton (2006). "Giving voice and making sense in interpretative phenomenological analysis". In: *Qualitative Research in Psychology* 3.2, pp. 102–120.
- Leder, D. (1990). "Clinical interpretation: the hermeneutics of medicine". In: *Theoretical Medicine* 11.1, pp. 9–24.

- Legg, A. M. and K. Sweeny (2013). "Do you want the good news or the bad news first? the nature and consequences of news order preferences". In: *Personality and Social Psychology Bulletin*, pp. 279–288.
- Lehn, D. v. and W. Gibson (2011). "Interaction and Symbolic Interactionism". In: *Symbolic Interaction* 34.3, pp. 315–318.
- Little, M. et al. (1998). "Liminality: a major category of the experience of cancer illness". In: *Social Science & Medicine* 47.10, pp. 1485–1494.
- Loge, J., S. Kaasa, and K. Hytten (1997). "Disclosing the cancer diagnosis: the patients' experiences". In: *European Journal of Cancer* 33.6, pp. 878–882.
- Lupton, D. (1996). "Your life in their hands: trust in the medical encounter". In: *Sociology of Health & Illness Monograph Series*, pp. 157–172.
- (1997). "Consumerism, reflexivity and the medical encounter". In: *Social Science & Medicine* 45.3, pp. 373–381.
- (2012). *Medicine as culture: illness, disease and the body*. London: SAGE Publications.
- Lutfe, K. and D. W. Maynard (1998). "Bad news in oncology: How physician and patient talk about death and dying without using those words". In: *Social Psychology Quarterly*, pp. 321–341.
- Macnaughton, J. (2011). "Medical humanities' challenge to medicine". In: *Journal of Evaluation in Clinical Practice* 17.5, pp. 927–932.
- Martis, L. and A. Westhues (2013). "A synthesis of the literature on breaking bad news or truth telling: Potential for research in India". In: *Indian Journal of Palliative Care* 19.1, p. 2.
- Mast, M. S., A. Kindlimann, and W. Langewitz (2005). "Recipients' perspective on breaking bad news: how you put it really makes a difference". In: *Patient Education and Counseling* 58.3, pp. 244–251.
- Maynard, D. W. (2003). *Bad news, good news: Conversational order in everyday talk and clinical settings*. Chicago: University of Chicago Press.
- McGann, P. and D. J. Hutson (2011). *Sociology of diagnosis*. Vol. 12. Bingley, UK: Emerald Group Publishing.
- McManus, R. (2012). *Death in a global age*. London: Palgrave Macmillan.
- McNamara, B. (2004). "Good enough death: autonomy and choice in Australian palliative care". In: *Social Science & Medicine* 58.5, pp. 929–938.
- McPherson, C. J., K. G. Wilson, and M. A. Murray (2007). "Feeling like a burden: exploring the perspectives of patients at the end of life". In: *Social Science & Medicine* 64.2, pp. 417–427.
- McQueen, A. (2009). "Waiting for a cancer diagnosis". In: *Cancer Nursing Practice* 8.4.
- Medical Council of New Zealand (2012). *New Zealand Medical Workforce 2012*. Tech. rep.
- Meier, D. E., A. L. Back, and R. S. Morrison (2001). "The inner life of physicians and care of the seriously ill". In: *JAMA, The Journal of the American Medical Association* 286.23, pp. 3007–3014.



- Merriam, S. B. et al. (2001). "Power and positionality: Negotiating insider/outsider status within and across cultures". In: *International Journal of Lifelong Education* 20.5, pp. 405–416.
- Mishler, E. G. (1986). *Research interviewing: context and narrative*. Cambridge, MA: Harvard University Press.
- Miyaji, N. T. (1993). "The power of compassion: truth-telling among American doctors in the care of dying patients". In: *Social Science & Medicine* 36.3, pp. 249–264.
- Mosenthal, A. C., K. F. Lee, and J. Huffman (2002). "Palliative care in the surgical intensive care unit". In: *Journal of the American College of Surgeons* 194.1, pp. 75–83.
- Moskowitz, R. (2010). "Diagnosis". In: *Medicine Studies* 2.2, pp. 121–137.
- Nuland Sherwin, B. (1994). *How we die: reflections on life's final chapter*. New York: Alfred A. Knopf.
- O'Mahony, S. (2013). "Against narrative medicine". In: *Perspectives in Biology and Medicine* 56.4, pp. 611–9.
- Page, S. and C. Komaromy (2005). "Professional performance: The case of unexpected and expected deaths". In: *Mortality* 10.4, pp. 294–307.
- Parker, P. A. et al. (2001). "Breaking bad news about cancer: patients preferences for communication". In: *Journal of Clinical Oncology* 19.7, pp. 2049–2056.
- Parsons, T. (1951). *The social system*. Glencoe, Illinois: Free Press.
- Plummer, K. (1995). *Telling sexual stories: Power, change and social worlds*. London: Routledge.
- Poulsen, M. G. et al. (2015). "Recovery experience and burnout in cancer workers in Queensland". In: *European Journal of Oncology Nursing* 19.1, pp. 23–28.
- Ramirez, A. et al. (1995). "Burnout and psychiatric disorder among cancer clinicians." In: *British Journal of Cancer* 71.6, p. 1263.
- Riessman, C. K. (1993). *Narrative analysis*. London: SAGE Publications.
- (2008). *Narrative methods for the human sciences*. London: SAGE Publications.
- Rosenberg, C. E. (2002). "The tyranny of diagnosis: specific entities and individual experience". In: *Milbank Quarterly* 80.2, pp. 237–260.
- Roth, M. et al. (2011). "Career burnout among pediatric oncologists". In: *Pediatric Blood & Cancer* 57.7, pp. 1168–1173.
- Salander, P. (2002). "Bad news from the patient's perspective: an analysis of the written narratives of newly diagnosed cancer patients". In: *Social Science & Medicine* 55.5, pp. 721–732.
- Schaepe, K. S. (2011). "Bad news and first impressions: patient and family caregiver accounts of learning the cancer diagnosis". In: *Social Science & Medicine* 73.6, pp. 912–921.

- Schofield, P. et al. (2006). "Would you like to talk about your future treatment options? Discussing the transition from curative cancer treatment to palliative care". In: *Palliative Medicine* 20.4, pp. 397–406.
- Schofield, P. et al. (2001). "Hearing the bad news of a cancer diagnosis: the Australian melanoma patient's perspective". In: *Annals of Oncology* 12.3, pp. 365–371.
- Seale, C. (1995). "Dying alone". In: *Sociology of Health & Illness* 17.3, pp. 376–392.
- (1998). *Constructing death: The sociology of dying and bereavement*. Cambridge: Cambridge University Press.
- (2000). "Changing patterns of death and dying". In: *Social Science & Medicine* 51.6, pp. 917–930.
- Seale, C. and S. van der Geest (2004). "Good and bad death: Introduction". In: *Social Science & Medicine* 58.5, pp. 883–885.
- Shanafelt, T. D. et al. (2014). "Burnout and career satisfaction among US oncologists". In: *Journal of Clinical Oncology*, JCO–2013.
- Shaw, J., S. Dunn, and P. Heinrich (2012). "Managing the delivery of bad news: an in-depth analysis of doctors delivery style". In: *Patient Education and Counseling* 87.2, pp. 186–192.
- Shaw, Brown, and Dunn (2013). "A qualitative study of stress and coping responses in doctors breaking bad news". In: *Patient Education and Counseling* 91.2, pp. 243–248.
- Shim, J. K., A. J. Russ, and S. R. Kaufman (2006). "Risk, life extension and the pursuit of medical possibility". In: *Sociology of Health & Illness* 28.4, pp. 479–502.
- Smith, J. A. (1996). "Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology". In: *Psychology and Health* 11.2, pp. 261–271.
- (2011). "Evaluating the contribution of interpretative phenomenological analysis: A reply to the commentaries and further development of criteria". In: *Health Psychology Review* 5.1, pp. 55–61.
- Smith, J. A., M. Larkin, and P. Flowers (2009). *Interpretative phenomenological analysis: theory, method and research*. London: SAGE Publications.
- Sokol, D. K. (2006a). "How the doctor's nose has shortened over time; a historical overview of the truth-telling debate in the doctor-patient relationship". In: *Journal of the Royal Society of Medicine* 99.12, pp. 632–636.
- (2006b). "Truth-telling in the doctor-patient relationship: a case analysis". In: *Clinical Ethics* 1.3, pp. 130–134.
- Starks, H. and S. B. Trinidad (2007). "Choose your method: A comparison of phenomenology, discourse analysis, and grounded theory". In: *Qualitative Health Research* 17.10, pp. 1372–1380.
- Stenmarker, M. et al. (2010). "Being a messenger of life-threatening conditions: Experiences of pediatric oncologists". In: *Pediatric Blood & Cancer* 55.3, pp. 478–484.

- Stevenson, F. (2004). "Concordance". In: *Social Theory & Health* 2.2, pp. 184–193.
- Sullivan, L. E. (2009). *The SAGE glossary of the social and behavioral sciences*. California: SAGE Publications.
- Sweeny, K. and J. A. Shepperd (2007). "Being the best bearer of bad tidings." In: *Review of General Psychology* 11.3, p. 235.
- Sweeny, K., J. A. Shepperd, and P. K. Han (2013). "The goals of communicating bad news in health care: do physicians and patients agree?" In: *Health Expectations* 16.3, pp. 230–238.
- Taylor, K. M. (1988). "Telling bad news: physicians and the disclosure of undesirable information". In: *Sociology of Health & Illness* 10.2, pp. 109–132.
- Thompson, A. G. (2007). "The meaning of patient involvement and participation in health care consultations: a taxonomy". In: *Social Science & Medicine* 64.6, pp. 1297–1310.
- Timmermans, S. (1994). "Dying of awareness: the theory of awareness contexts revisited". In: *Sociology of Health & Illness* 16.3, pp. 322–339.
- (2005). "Death brokering: constructing culturally appropriate deaths". In: *Sociology of Health & Illness* 27.7, pp. 993–1013.
- Todorova, I. (2011). "Explorations with interpretative phenomenological analysis in different socio-cultural contexts: Commentary on J. Smith: Evaluating the contribution of interpretative phenomenological analysis". In: *Health Psychology Review* 5.1, pp. 34–38.
- Wallace, J. E. (2010). "Mental health and stigma in the medical profession". In: *Health*: pp. 3–18.
- William, L. and J. Waletzky (1967). "Narrative Analysis: Oral Versions of Personal Experience". In: *Essays on the Verbal and Visual Arts*. Ed. by J. Helm. Seattle: University of Washington Press, pp. 12–44.
- Williams, S. J. (2005). "Parsons revisited: from the sick role to...?" In: *Health* 9.2, pp. 123–144.
- Willig, C. (2011). "Cancer diagnosis as discursive capture: Phenomenological repercussions of being positioned within dominant constructions of cancer". In: *Social Science & Medicine* 73.6, pp. 897–903.
- Windsor, J. A. et al. (2008). "Telling the truth to Asian patients in the hospital setting". In: *The New Zealand Medical Journal* 121.1286.
- Wood, W. A., M. S. McCabe, and R. M. Goldberg (2009). "Commentary: disclosure in oncology to whom does the truth belong?" In: *The Oncologist* 14.1, pp. 77–82.
- Xue, D., J. L. Wheeler, and A. P. Abernethy (2011). "Cultural differences in truth-telling to cancer patients: Chinese and American approaches to the disclosure of bad news". In: *Progress in Palliative Care* 19.3, pp. 125–131.
- Zier, L. S. et al. (2012). "Surrogate decision makers' interpretation of prognostic information". In: *Annals of Internal Medicine* 156.5, pp. 360–6.

- Zimmermann, C. (2007). "Death denial: obstacle or instrument for palliative care? An analysis of clinical literature". In: *Sociology of Health & Illness* 29.2, pp. 297–314.